

# IntegratedEthics

Improving Ethics Quality in Health Care



## Ethics Consultation

Responding to Ethics Concerns in Health Care



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## ***The National Center for Ethics in Health Care***

The National Center for Ethics in Health Care (Ethics Center) is the Veterans Health Administration's (VHA's) national program office responsible for addressing the complex ethics issues that arise in patient care, health care management, and research. The Ethics Center has many years of experience in health care ethics consultation and provides support for VHA leadership, local ethics committees, and field-based staff. Our multidisciplinary team includes health care ethics experts in medicine, nursing, philosophy, theology, anthropology, public health, business, and law.

### ***IntegratedEthics***

This document was produced by the Ethics Center as a component of its IntegratedEthics initiative, an innovative national education and organizational change project that takes its name and its philosophy from the recognition that in health care today, ethical challenges cannot be fully met by a discrete committee that operates in relative isolation from the rest of the organization it serves. Neither can they be met by activities occurring in a disconnected fashion all over the organization. A more systematic, integrated approach is needed.

To respond to this need, the IntegratedEthics initiative provides VHA facilities with tools to transform their traditional ethics committees into *IntegratedEthics programs*. The initiative emphasizes distance learning and combines print materials, video and online courses, evaluation tools, and supporting resources (teleconferences, website, listserv, and technical support).

An IntegratedEthics program is a *local mechanism within a health care organization designed to promote ethical health care practices*. In contrast to traditional ethics committees, which typically define their role in terms of the activities they perform (education, consultation, and policy development), IntegratedEthics programs define their role in terms of their ultimate goal: to improve ethics quality in health care.

What do we mean by ethics quality in health care? That an organization's health care practices are consistent with widely accepted ethical standards, norms, and expectations for conduct. Ethics quality is the product of the interplay of factors at three levels: individual decisions and actions, organizational systems and processes, and environment and culture.

An IntegratedEthics program improves ethics quality by targeting each of these levels through one of its three core functions:

1. **Ethics Consultation:** responding to ethics concerns in health care
2. **Preventive Ethics:** addressing health care ethics issues on a systems level
3. **Ethical Leadership:** fostering a positive health care ethics environment

The structure of an IntegratedEthics program will vary according to the needs and opportunities in a given facility. Essentially, “form follows function.” There are only a handful of givens:

- Each program must have an IntegratedEthics Coordinator. The IntegratedEthics Coordinator should be a respected member of the facility staff and a skilled manager, who will direct the program overall, coordinate its three functions, and ensure that the program is well integrated with other parts of the facility.
- The IntegratedEthics Coordinator must report directly to a member of the senior management team who will champion the program and take responsibility for its overall success.
- There must be someone responsible for each of the three core functions: ethics consultation, preventive ethics, and ethical leadership. These coordinators should have the knowledge, skills, and support required to succeed in their respective roles. The Ethical Leadership Coordinator should be either the member of the senior management team who is responsible for the success of the program, or a member of the senior manager’s immediate staff.
- Each of the three functions must be addressed systematically and in an integrated fashion.

With these assumptions in mind, each facility should assess its existing organizational structure and figure out what will work best locally. The goal is to develop a structure that will build on the strengths of a facility’s current ethics committee or program to assure that health care ethics thinking is pervasive up and down the organization’s decision-making hierarchy and across all services, programs, and settings.

How comprehensive is an IntegratedEthics program? It works to improve ethics quality across a broad range of health care ethics domains:

- Health care ethics environment (how well the facility supports ethical health care practices overall)
- Shared decision making (how well the facility promotes collaborative decision making between clinicians and patients)
- End-of-life care (how well the facility addresses ethical aspects of caring for patients near the end of life)
- Privacy and confidentiality (how well the facility protects patient privacy and confidentiality)
- Professionalism (how well the facility fosters employee behavior that reflects professional standards)
- Resource allocation (how well the facility ensures fairness in the way it allocates its resources across programs, services, and patients)

An IntegratedEthics program also supports the efforts of other offices and programs [listed in brackets] to improve ethics quality in three additional domains, as appropriate:

- Business ethics [Compliance and Business Integrity] (e.g., business practices, including coding and billing)
- Government ethics [Regional Counsel] (e.g., standards of ethical conduct for government employees)
- Research ethics [Research and Development] (e.g., human subjects research)

### **About this Document**

*Ethics Consultation: Responding to Ethics Concerns in Health Care* establishes VHA guidance for the one of the three core functions of IntegratedEthics: Ethics Consultation.

It was designed as a primer, to be read initially in its entirety by everyone who participates in ethics consultation, including leaders responsible for overseeing the ethics consultation function. Subsequently, it can serve as a useful reference document when consultants wish to refresh their memories or to answer specific questions.

Part I, “Introduction to Ethics Consultation in Health Care,” provides an overview of health care ethics consultation, outlines the proficiencies required to perform ethics consultation, and reviews other factors necessary for success.

Part II, “CASES: A Step–by–Step Approach to Ethics Case Consultation,” describes in detail a practical, systematic process for performing ethics consultations pertaining to active patient cases.

The appendices provide additional resources, a glossary, and practical tools to (1) assess consultants’ proficiency for performing ethics consultation, (2) obtain feedback from ethics consultation participants, (3) remind consultants of the steps in the CASES approach, and (4) appropriately document ethics consultation activities.

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## ***Part I***

### Introduction to Ethics Consultation in Health Care



## **What Is Ethics Consultation in Health Care?**

### ***The importance of ethics in health care***

Throughout our health care system, patients and health care professionals must make difficult, potentially life-altering decisions every day. Making decisions like these can stir up controversy or cause us to re-examine our fundamental values and beliefs. In the business of health care, situations that raise ethics concerns—that is, uncertainties or conflicts about values—inevitably arise.

Effectively responding to ethics concerns is essential to high quality patient care. Unresolved ethics concerns can lead to errors or unnecessary and potentially costly delays in care decisions, and thus can be bad for patients, providers, and the organization.<sup>1-4</sup> When employees perceive that they have no place to bring their ethics concerns, this can result in moral distress, which is recognized to be a major cause of professional “burnout.”<sup>5</sup> In addition, ethics concerns often signal underlying systems problems that need to be addressed, such as policies that are not well aligned with organizational mission and values.

In fact, ethics and quality are inextricably linked. To say that health care is of high quality implies adherence to established professional and ethical standards. In other words, health care providers who violate recognized ethical standards cannot be described as delivering high quality care. By the same token, patient care that falls short of minimal quality standards can be ethically problematic. Thus ethical practice and quality care can never be truly separated.

### ***Ethics consultation defined***

For the purposes of this document, we define **health care ethics consultation** as a service provided by an individual ethics consultant, ethics consultation team, or ethics committee to help patients, providers, and other parties resolve ethics concerns in a health care setting.

### ***The goals of ethics consultation***

The overall goal of health care ethics consultation is to *improve health care quality by facilitating the resolution of ethics concerns that arise in health care*. By providing a forum for discussion and a method of careful analysis, effective ethics consultation:

- Promotes health care practices consistent with high ethical standards
- Helps to foster consensus and resolve conflict in an atmosphere of respect
- Honors participants’ authority and values in the decision-making process
- Educates participants to handle current and future ethics concerns

### ***A brief history of ethics consultation***

Ethics consultation in health care settings dates back nearly 35 years. In the 1970s the first consultation services were established. In the 1980s a professional society devoted to ethics consultation was established, and the first books on ethics consultation were published.<sup>6,7</sup> In the mid-1990s a national consensus conference described goals of ethics consultation and methods for evaluating its quality and effectiveness.<sup>8</sup> In 1998 the American Society for

Bioethics and Humanities published *Core Competencies for Health Care Ethics Consultation*, a report that describes the proficiencies required for health care ethics consultation.<sup>9</sup>

### ***Health care ethics consultation today***

Ethics consultation is now widely recognized as an essential part of health care delivery. The vast majority of U.S. hospitals have active ethics consultation services.<sup>10</sup> The Joint Commission for Accreditation of Healthcare Organizations requires that hospitals develop and implement a process to handle ethics concerns when they arise.<sup>11</sup> The Malcolm Baldrige National Quality Award Program recognizes “ethical practices in all stakeholder transactions and interactions” as a key criterion for performance excellence.<sup>12</sup> Moreover, ethics consultation has been endorsed by numerous governmental and professional bodies, and is legally mandated under specific circumstances in several states.<sup>13</sup>

Effective ethics consultation has been shown to improve ethical decision making and practice, enhance patient and provider satisfaction, facilitate the resolution of disputes, and increase knowledge of health care ethics.<sup>14</sup> Moreover, ethics consultation has been shown to save health care institutions money by reducing the provision of nonbeneficial treatments, as well as lengths of stay.<sup>1-4</sup>

### ***The ethics consultation service***

It is therefore essential for every health care facility to have an effective local mechanism for responding to ethics concerns—that is, an ***ethics consultation service***. Ethics consultation services handle ***ethics case consultations***, as well as other types of consultations, including requests for general information, policy clarification, document review, discussion of hypothetical or historical cases, or ethical analysis of an organizational ethics question.

## **What Models May Be Used to Perform Ethics Consultation?**

Health care ethics consultation may be performed by an individual ethics consultant, an ethics committee, or an ethics consultation team.

As discussed below, each of these models has advantages and disadvantages. Although some ethics consultation services might rely exclusively on one of these three models, we generally recommend against this, since all three models have their place. Instead, *ethics consultation services should determine, for each consultation, which of the three models is most appropriate*. Ethics consultation services should have consistent processes for determining how different types of consultations will be handled.

### ***Individual ethics consultant model***

In this model, one person—either an independent “solo” consultant or a member of an ethics consultation team or committee—is assigned to perform a given consultation individually.

#### ***Advantages:***

- Fewer logistical hurdles (e.g., scheduling meetings)
- Quicker response to urgent consultation requests

#### ***Disadvantages:***

- The consultant must possess all required knowledge and skills
- Fewer checks and balances to protect against consultants’ personal biases

It is incumbent on the individual ethics consultant to recognize his or her limitations and get help when needed. The successful ethics consultant will build a web of strong, collegial relationships within his or her facility and network, and will call on others for assistance with particular ethical, legal, cultural, or religious concerns. Even the most highly trained and experienced ethics consultant benefits from discussing complex cases with outside experts. In addition, individual consultants should engage in some form of systematic review of their consultations with colleagues.

*The individual ethics consultant model is generally appropriate only for the most straightforward consultations or for the most proficient ethics consultants.*

### ***Ethics committee model***

In this model, a standing interdisciplinary committee—that is, a relatively stable group of people (typically between 6 and 20)—jointly performs a given consultation.

#### ***Advantages:***

- Facilitates collective proficiency
- Includes ready access to diverse perspectives and multidisciplinary expertise

*Disadvantages:*

- Requires a great deal of staff time
- Not well suited to situations that require a rapid response
- Diffusion of responsibility across committee members can contribute to complacency and “groupthink”
- Patients and family members may feel intimidated by a large group of professionals

*The committee model may be especially useful for assuring broad organizational input into difficult consultations, including those that might establish precedent or end up in the media or the courts. This model may also be useful to facilities that are relatively new to ethics consultation, handle a low volume of consultations, and/or lack specialized ethics expertise.*

**Ethics consultation team model**

In this model, responsibility for a given ethics consultation is shared by a small group of people (typically between 2 and 4), who are selected from a pool of qualified consultants based on their complementary perspectives and expertise relevant to the circumstances.

*Advantages:*

- Several perspectives and diverse expertise
- Flexibility for a rapid response
- Composition of team can vary to meet the situation
- Less intimidating for patients and families
- A natural forum for support and reflection

*Disadvantages:*

- Less efficient than the individual consultant model
- Fewer checks and balances than the committee model

This model allows for tasks to be divided up among members of the team. For example, it is not necessary for every team member to go to the patient’s bedside or attend a family meeting. A single member may perform each of these roles and then report back to the others on the team. Deciding which member of the team has the best skills and knowledge to take the lead for a particular consultation calls for insight and good judgment.

*The team model accommodates a wide range of situations and levels of consultant expertise and is in some ways a compromise between the individual and committee models. It is the most common model, used by more than two-thirds of hospitals in the United States, both within and outside VHA.<sup>10</sup>*

## **What Proficiencies Are Required to Perform Ethics Consultation?**

The 1998 ASBH report *Core Competencies for Health Care Ethics Consultation*<sup>9</sup> discusses the knowledge, skills, and character traits required for ethics consultation, and notes that when an individual consultant performs ethics consultation, the consultant must have advanced knowledge and skills across multiple areas. In contrast, when the team or committee model is used, requisite knowledge and skills can be distributed across the various members of the group.

Of course, the greater the collective expertise within an ethics consultation service, the more useful and effective that service will be. Although basic knowledge and skills may be developed through practical experience, development of advanced knowledge and skills generally requires a more rigorous and systematic approach to learning (e.g., formal coursework, in-depth reading and discussion, supervised practice with feedback).

The knowledge, skills, and character traits described below are adapted from the ASBH report.

### **Knowledge**

Successful ethics consultation requires knowledge of:

- Moral reasoning and ethics theory, including familiarity with a variety of approaches to ethical analysis, such as principle-based and casuist
- Bioethics issues and concepts in the areas of shared decision making, end-of-life care, privacy and confidentiality, professionalism, resource allocation, and research with human subjects
- Health care practices, especially clinical literacy—i.e., the ability to understand medical terms, and descriptions of disease processes, treatments, and prognoses; familiarity with medical decision making, current or emerging technologies, and the different roles, relationships, and expertise of health care providers
- Cultural and religious issues, including how culture, religious tradition, ethnicity, beliefs, and perspectives shape both providers' and patients' responses to illness, death, and medical treatment
- Health care environment, including VHA and local facility mission statements, organizational structures, range of service and points of care, and policies (including those on informed consent, advance directives, privacy and confidentiality, and orders not to resuscitate)
- Health law, significant legal cases and concepts, and relevant codes of ethics and professional conduct

### **Skills**

Ethics consultation also requires specific skills. Those who perform ethics consultation must be able to:

- Identify the nature of the uncertainty at the heart of the case
- Analyze the ethics concerns
- Identify and evaluate the ethically justifiable options
- Facilitate formal and informal meetings, including those involving highly charged issues or participants who may be emotionally distressed
- Build consensus when there are competing moral views and/or multiple ethically justifiable options
- Collect and verify clinical and other relevant information
- Demonstrate critical thinking
- Listen well
- Communicate effectively and respectfully
- Recognize and address barriers to communication
- Foster a respectful, supportive environment for expression of moral views
- Educate participants about ethics issues
- Document consultations in the medical and consultation service records
- Use institutional resources effectively
- Evaluate consultations

### **Character traits**

Ethics consultants should also display certain character traits. For example, when appropriate, consultants should exhibit:

- Humility
- Tolerance
- Patience
- Compassion
- Honesty
- Forthrightness
- Self-knowledge
- Prudence
- Integrity
- Courage

Individuals who are unable to demonstrate these traits when the situation demands it are generally not well suited to perform ethics consultation.

**Appendix 1** provides an assessment tool for evaluating the proficiency of ethics consultants.



## **What Are the Critical Success Factors for Ethics Consultation?**

Although the empirical evidence on ethics consultation is limited, we have observed that certain factors are critical for an ethics consultation service to achieve its goals. Ethics consultation services need to have *integration, leadership support, expertise, staff time, and resources*. *Access, accountability, organizational learning, and evaluation* are additional factors that should be assured. Since all these factors are critical for the success of ethics consultation services, they should be described in *policy*.

### **Integration**

The successful ethics consultation service does not function as a silo, but develops and maintains positive relationships with the various individuals and programs that shape the organization's health care ethics environment and practices. In this way, it serves the entire institution, not just a particular category of staff (such as physicians), a particular setting (such as intensive care), or a particular clinical service (such as surgery). A fully integrated ethics consultation service responds to the full range of ethics concerns faced by the organization.

Integration is also reflected in strong connections between the ethics consultation service and other departments and services within the organization. The ethics consultation service should look for opportunities to share activities and skills, or to identify and work to achieve mutual goals. For example, the ethics consultation service might enlist the facility's quality management program to help evaluate the service's performance. In addition, the ethics consultation service should develop ongoing working relationship with other facility programs and departments that commonly encounter ethics-related issues (e.g., chaplain service, patient advocate program, legal counsel, research, compliance, human resources). The establishment of these relationships will help promote collaboration, and ensure that staff across different services and programs understand each others' skills and roles, thereby contributing to the overall efficiency of the organization.

### **Leadership support**

Explicit leadership support is essential if the goals of ethics consultation are to be realized. Ultimately, leaders are responsible for the success of all programs, and health care ethics consultation is no exception. It is leaders who establish organizational priorities and allocate resources to support those priorities. *Unless leaders support—and are perceived to support—the ethics consultation function in a facility, the consultation function cannot succeed.*

Leaders can and should support an ethics consultation service in several ways:

- Understand the scope and role of the ethics consultation service
- Keep up to date on the activities of the ethics consultation service
- Regularly update staff on those activities
- Seek advice from the ethics consultation service when appropriate
- Encourage others to utilize the ethics consultation service
- Set out responsibilities of ethics consultation in staff performance plans

- Recognize staff for their ethics consultation activities
- Ensure that other critical success factors are in place, as described below

### **Expertise**

Health care facility leaders should assure that ethics consultation services have the requisite expertise. Regardless of the consultation model used, all of the proficiencies outlined in the previous section of this document must be represented within the ethics consultation service. Individual members of the service may have different proficiencies, and some proficiencies may be represented by only one person. Collectively, however, the full set of core competencies must be represented on the service.

Most facilities should recruit or train their own in-house ethics consultants. Where this is not a realistic option, facilities need, at least, to arrange access to outside experts. For example, some VA facilities engage the services of an outside ethics consultant on a contractual or fee basis—this may be most appropriate for small facilities that handle only a few consultations a year. Other facilities may choose to establish agreements with a university affiliate's health care ethics program.

**Appendix 1** provides an assessment tool for evaluating the proficiency of ethics consultants.

### **Staff time**

Health care facility leaders should also assure that adequate staff time is available for ethics consultation activities. Ethics consultation can be time consuming, and individuals responsible for this service need dedicated time to do their work. In a given facility, the time required for ethics consultation will vary depending on the types of consultations handled. For example, even a straightforward ethics case consultation will typically take several person-hours, while more complex cases—especially those that are novel or precedent setting—may require many hours from multiple individuals over an extended period of time. Depending on the circumstances, a consultation may take place over a week or more and add up to 20 person-hours or more of effort.

Moreover, in addition to case consultations, ethics consultation services handle a variety of other types of requests, including requests for general information or education, clarification of policy, review of documents, or ethical analysis of hypothetical or historical (nonactive) cases or organizational ethics questions. When all of the person-hours devoted to ethics consultation are taken into account, the most active of ethics consultation services may require a time commitment equivalent to a dedicated full-time staff member (FTE).

*Consultation should not be viewed as an optional or voluntary activity, but as an assigned part of employees' jobs that requires dedicated time.* Individuals who participate in ethics consultation should have a clear understanding with their supervisors regarding how much time this activity involves.



## Resources

Health care facility leaders should also assure that individuals performing ethics consultation have ready access to other resources they need, such as library materials, clerical support, training, and continuing education. Because many facility libraries do not have a good selection of health care ethics references, an ethics consultation service often needs its own core set of books and journals. Because a variety of useful ethics resources are available online, access to the Internet is essential as well. An ethics consultation service also requires administrative support, such as clerical assistance, and space in which to store its files and perform its work. Finally, ethics consultants need training and regular continuing education to develop, maintain, and improve their knowledge and skills.

## Access

To be effective, an ethics consultation service must be accessible to the patients, families, and staff it serves. The service should be available not only in acute care hospitals, but across all points of care. Typically, ethics consultation services are most active in inpatient settings. Yet ethics concerns are also common in outpatient clinics, long-term care facilities, home care, and other settings. *Ethics consultation services should take steps to assure that, across various sites of health care delivery, patients and staff are aware of the ethics consultation service, what it does, and how to access it.* The service should be publicized through brochures, posters, newsletters, and other media through which patients and staff regularly receive information about the facility.

Like most other health care services, the ethics consultation service should be available throughout normal work hours. This means that whenever someone attempts to contact the service, a consultant will get back in touch with that person in a timely fashion (e.g., within one business day for routine requests, and as soon as possible on the same day for urgent requests). After-hours coverage arrangements may vary. In facilities where the volume of consultation requests is high, ethics consultants should be available by beeper over weekends, nights, and holidays. In other facilities where there are fewer ethics consultations, requests may be triaged by an administrator who has access to an ethics consultant as needed.

It is most desirable for ethics consultants to work on site, but in some facilities this may not be possible. In such circumstances, consultants must rely on videoconferencing, teleconferencing, and, possibly, to a lesser extent, encrypted e-mail or secure online messaging. Such methods may be unavoidable for geographically remote facilities, but must be used cautiously. Consultants working off site must overcome a variety of obstacles. For example, the consultant may have difficulty gaining access to the patient's health record. It may be logistically impossible to interview a patient on a ventilator in the ICU because he cannot talk on the telephone. And it can be challenging to establish trusting relationships without face-to-face meetings. Consultants who work off site must make special efforts to overcome these sorts of obstacles.

Requests for ethics case consultations (i.e., consultations that pertain to an active patient case) should only be accepted from someone who has “standing” in the case—that is, a person who is rightfully involved. For example, the patient and his or her close family members would have standing in a case, as would those clinical staff, medical students, and administrators who are directly responsible for the patient's care. Individuals who would not have standing might include a member of the media or a health care worker who was not assigned to the patient but heard about the case secondhand.

While requests for ethics case consultation should only be accepted from someone who has standing in the case, requests for other types of consultation should be accepted from a broad range of individuals connected to the facility. Noncase consultations might include, for example, requests for policy clarification or document review.

Anonymous requests for ethics consultation are problematic for a variety of reasons and, as a rule, should not be accepted. The concept of service is central to ethics consultation. When no one is identified as the requester, it is unclear whom the consultation serves, and it may be perceived as more meddlesome than helpful. Moreover, if the requester remains anonymous, the consultant cannot clarify the nature of his or her concern(s), or determine whether the requester has standing in the case. In addition, anonymous requests typically amount to allegations of unethical conduct, which must be addressed through other means. An ethics consultation service cannot be effective if it earns the label of “ethics police.” If an anonymous request suggests a serious breach of compliance with facility policy or the law, it should not be accepted as a consultation; the consultant should refer the requester to the appropriate institutional office or service.

Occasionally, an individual requests an ethics consultation in a nonanonymous fashion, but asks to have his or her identity protected. Most commonly, trainees, nurses, or others who feel vulnerable within the organization make such requests. The consultant should privately explore why the requester does not wish to be identified. If the request is for a noncase consultation, the consultation can usually proceed—however, the consultant should then generally either encourage the requester to proceed without an expectation of confidentiality, or examine alternative mechanisms to address the concern. In rare circumstances, the consultant might decide to proceed with an ethics case consultation while trying to protect the identity of the requester, who should be warned that although the ethics consultation team will not intentionally reveal the requester’s identity, others might infer it.

### **Accountability**

Like any other important health care function, ethics consultation must have a clear system of accountability and must be clearly situated within the reporting hierarchy. *Day-to-day responsibility for the activities of the ethics consultation service should rest with a designated individual, the Ethics Consultation Coordinator.* The involvement of senior management is also crucial. Specifically, responsibility for a facility’s health care ethics program—of which ethics consultation is an integral part—should rest with a designated senior institutional leader, such as the Chief of Staff. To assure accountability, responsibilities relating to ethics consultation should be clearly described in the performance plans of everyone involved, from senior leaders to frontline staff.

The consultation service should disseminate information about its activities, accomplishments, and findings, and keep organizational leaders up to date about the service, its successes and failures, and whether it is accomplishing its goals. Those involved in ethics consultation should provide leadership with regular feedback regarding their activities, obstacles, and successes. This feedback could be as simple as sending individual service records to selected leaders and flagging items that may be of particular interest to them, or as complex as developing a quarterly or annual report of ethics consultation activities. Similar reports, when distributed more broadly to facility staff, serve as a useful reminder of the service’s existence, availability, and value.

### **Organizational learning**

It is important for ethics consultants to contribute to organizational learning by sharing their knowledge and experience. Group discussion of actual cases (appropriately modified to protect the identities of participants) is an excellent way to educate clinical staff. With relatively little effort, a consultation service note can be reworked into a newsletter article that summarizes an important ethics topic. Policy questions handled by the service can be turned into Frequently Asked Questions and posted on a website. Efforts such as these not only enhance staff knowledge, they also enhance the credibility and visibility of the ethics consultation service.

### **Evaluation**

Assuring the success of the ethics consultation service also requires ongoing evaluation, where evaluation is defined as the systematic assessment of the operation and/or outcomes of a program, compared to a set of explicit or implicit standards, as a means of contributing to the continuous improvement of the program.<sup>15</sup> *This document establishes explicit standards for ethics case consultation against which actual practices may be compared.*

For example, the critical success factors identified in this section should be systematically assessed:

- *Integration:* Is the consultation service well integrated with other components of the organization?
- *Leadership support:* Is the ethics consultation service sufficiently supported by leadership?
- *Expertise:* Do ethics consultants have the knowledge and skills required?
- *Staff time:* Do ethics consultants have adequate time to perform effectively?
- *Resources:* Do ethics consultants have ready access to the resources they need?
- *Access:* Is the ethics consultation service accessible to those it serves?
- *Accountability:* Is there clear accountability for ethics consultation within the facility's reporting hierarchy? Does the consultation service keep leadership apprised of its activities?
- *Organizational learning:* Is the ethics consultation service effectively disseminating its experience and findings?
- *Evaluation:* Does the ethics consultation service continuously improve its quality through systematic assessment?
- *Policy:* Are the structure, function, and processes of ethics consultation formalized in institutional policy?

Additionally, assessments should be made to determine whether ethics case consultations are performed in accordance with the approach outlined in Part II, "CASES: A Step-by-Step Approach to Ethics Case Consultation."

Finally, efforts should be made to determine whether the ethics consultation service is meeting its professed goals. For example, does the service promote health care practices consistent with high ethical standards? Does it help to resolve conflicts in a respectful

manner? Does it honor participants' authority and values in decision making? Does it effectively educate participants to handle current and future ethics concerns?

Evaluation is an important strategy to improve the process of ethics consultation (i.e., how it is being implemented) as well as its outcomes (i.e., how ethics consultation affects participants and the facility). Evaluation efforts need not be burdensome or costly. Experts within the facility, such as quality managers, can assist with developing appropriate ways to assess these factors to assure that the measures used are valid, and that data are collected and analyzed in a minimally burdensome fashion.

**Appendix 2** provides an assessment tool for evaluating the ethics consultation service.

### ***Policy***

The structure, function, and processes of ethics consultation should be formalized in institutional policy. At a minimum, this policy should address the following topics:

- The goals of ethics consultation
- Who may perform ethics consultation
- Who may request ethics consultations
- What requests are appropriate for the ethics consultation service
- What requests are appropriate for ethics case consultation
- Which consultation model(s) may be used and when
- Who must be notified when an ethics case consultation has been requested
- How the confidentiality of participants will be protected
- How ethics consultations will be performed
- How ethics consultations will be documented
- Who is accountable for the ethics consultation service
- How the quality of ethics consultation will be assessed and assured

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## ***Part II***

### **CASES: A Step-by-Step Approach to Ethics Case Consultation**

## Using the CASES Approach

This section describes the CASES approach, a practical, systematic approach to ethics consultation. This approach involves five steps:

C

### **CLARIFY** the Consultation Request

*Confirm that the request is appropriate for ethics case consultation*  
*Obtain preliminary information from the requester*  
*Establish realistic expectations about the consultation process*  
*Formulate the ethics question*

A

### **ASSEMBLE** the Relevant Information

*Consider the types of information needed*  
*Identify the appropriate sources of information*  
*Gather information systematically from each source*  
*Summarize the case and the ethics question*

S

### **SYNTHESIZE** the Information

*Determine whether a formal meeting is needed*  
*Engage in ethical analysis*  
*Identify the ethically appropriate decision maker*  
*Facilitate moral deliberation about ethically justifiable options*

E

### **EXPLAIN** the Synthesis

*Communicate the synthesis to key participants*  
*Provide additional resources*  
*Document the consultation in the health record*  
*Document the consultation in consultation service records*

S

### **SUPPORT** the Consultation Process

*Follow up with participants*  
*Evaluate the consultation*  
*Adjust the consultation process*  
*Identify underlying systems issues*



These steps were designed to guide ethics consultants through the complex process needed to effectively address ethics concerns in health care. We intend this set of steps to be used similarly to the way clinicians use a standard format for taking a patient's history, performing a physical exam, or writing up a clinical case. Even when some steps do not require specific, observable action, each of the steps should be considered systematically as part of every ethics case consultation.

Although the steps are presented in a linear fashion, it should be recognized that *ethics case consultation is a fluid process and the distinction between steps may blur in the context of a specific case*. At times, it may be necessary to repeat steps or perform them in a different order than presented here.

How much time should it take for each step in the CASES approach? There is no simple answer to this question. The experienced consultant can judge the time requirements of a particular consultation and respond appropriately. How much time it will take to complete any given step depends on the question being addressed, the composition and experience of the consultation service, the model of consultation employed, the time and resources available, and other circumstances unique to the clinical and organizational context. Some ethics consultations may be completed the same day a request is received; others may take significantly longer. Rushing a consultation can lead to mistakes, as can responding too slowly.

**Appendix 3** provides a pocket card summarizing the CASES approach.

## Step 1: Clarify the Consultation Request

The first step in the CASES approach is to clarify the request. The consultant should gather information from the requester to form a preliminary understanding of the situation and why an ethics consultation is being sought.



### CLARIFY the Consultation Request

*Confirm that the request is appropriate for ethics case consultation*  
*Obtain preliminary information from the requester*  
*Establish realistic expectations about the consultation process*  
*Formulate the ethics question*

#### **Confirm that the request is appropriate for ethics case consultation**

Before doing anything else, the consultant should determine whether the request is appropriate for ethics case consultation by considering these two questions:

**Question 1: Does the requester want help resolving an ethics concern?** The role of the ethics consultation service is to help patients, providers, and other parties in a health care setting resolve *ethics concerns*, i.e., uncertainties or conflicts about values. In this context, values are strongly held beliefs, ideals, principles, or standards that inform ethical decisions or actions. These might include a belief that people should never be allowed to suffer, an ideal that no one should be discriminated against on the basis of his or her religion, the principle that health care workers have a duty to be truthful with patients, or the standard of informed consent. Individuals with ethics concerns may seek values clarification and/or resolution of values conflicts.

As a general principle, if the requester thinks that a circumstance raises an ethics concern, the assumption should be that it does. However, requesters may sometimes contact the ethics consultation service seeking assistance with concerns that are better handled by other offices or programs, such as legal questions, medical questions, requests for psychological or spiritual support, general patient care complaints, or allegations of misconduct.

*If the answer to Question 1 is no—that is, the requester wants something other than assistance resolving uncertainty or conflict about values—then the request is not appropriate for ethics consultation.* Requests that do not pertain to ethics concerns should be referred to other offices within the organization. For example:

- *Legal questions (e.g., “Will the facility get in trouble if we accept a commemorative plaque from a pharmaceutical company?” or “If we refuse to do the MRI, can the patient sue us?”) should be referred to Regional Counsel or the VA Office of General Counsel. Often requesters who are seeking legal advice want assistance resolving an ethics concern as well. When a question involves both legal and ethical concerns, the legal aspect should be referred to legal counsel and the ethical concerns addressed by the ethics consultation service.*
- Note that matters pertaining to **government ethics** are actually legal matters, since the term “government ethics” refers to a specific set of legal restrictions that apply to federal employees, mostly pertaining to the use of public office for private gain.



- *Medical or clinical questions* (e.g., “Will this patient regain decision-making capacity?” or “Does this Jehovah’s Witness patient really need a blood transfusion?”) should be referred to an appropriate clinical resource, service chief, or the Chief of Staff.
- Requests for *psychological or spiritual support* (e.g., “As a doctor, I am having trouble coming to terms with my mistake” or “Someone needs to talk to the wife about her husband’s impending death”) should be referred to the local Employee Assistance Program, chaplain service, social work program, or other mental health professional, as appropriate.
- General *patient care complaints* (e.g., “The doctor is insensitive and doesn’t listen to me” or “I’m concerned that this nurse may have a substance abuse problem”) should be referred to medical center administration, the local patient advocate program, the Office of the Medical Inspector, or other appropriate office or program.
- *Allegations of misconduct* (e.g., “Staff are backdating entries in the health record” or “That doctor is diverting VA patients to his university clinic practice”) should be referred to the local Compliance Officer, medical center administration, the Compliance and Business Integrity Helpline, the VA Office of the Inspector General Hotline, or other appropriate office or program.

*If the answer to Question 1 is yes, consider Question 2.*

**Question 2: Does the request pertain to an active patient case?** *If the answer to Question 2 is no, the request is appropriate for ethics consultation, but is not an ethics case consultation.* In addition to handling ethics case consultations (that is, consultations on active patient cases), the consultation service may also handle noncase consultations, including requests to:

- Answer questions about topics in health care ethics
- Interpret policy relating to health care ethics
- Review documents from a health care ethics perspective
- Provide ethical analysis on organizational ethics questions
- Provide ethical analysis on patient cases that are hypothetical or historical (nonactive)

Although the CASES approach was designed especially for ethics consultations on active patient cases, the steps in the CASES approach may be relevant to other ethics consultations as well. For example, it is always important to clarify the question and do a thorough job of collecting information. For a hypothetical case, the consultant might go through all the steps but would not be able to interview participants.

*If the answer to Question 2 is yes (i.e., the request pertains to an active patient case), the request should be handled through the CASES approach (or a similar systematic approach).* Working systematically through all the stages of the process is essential to ensure the quality of ethics consultation, even when members of an ethics consultation service are pressed for time.

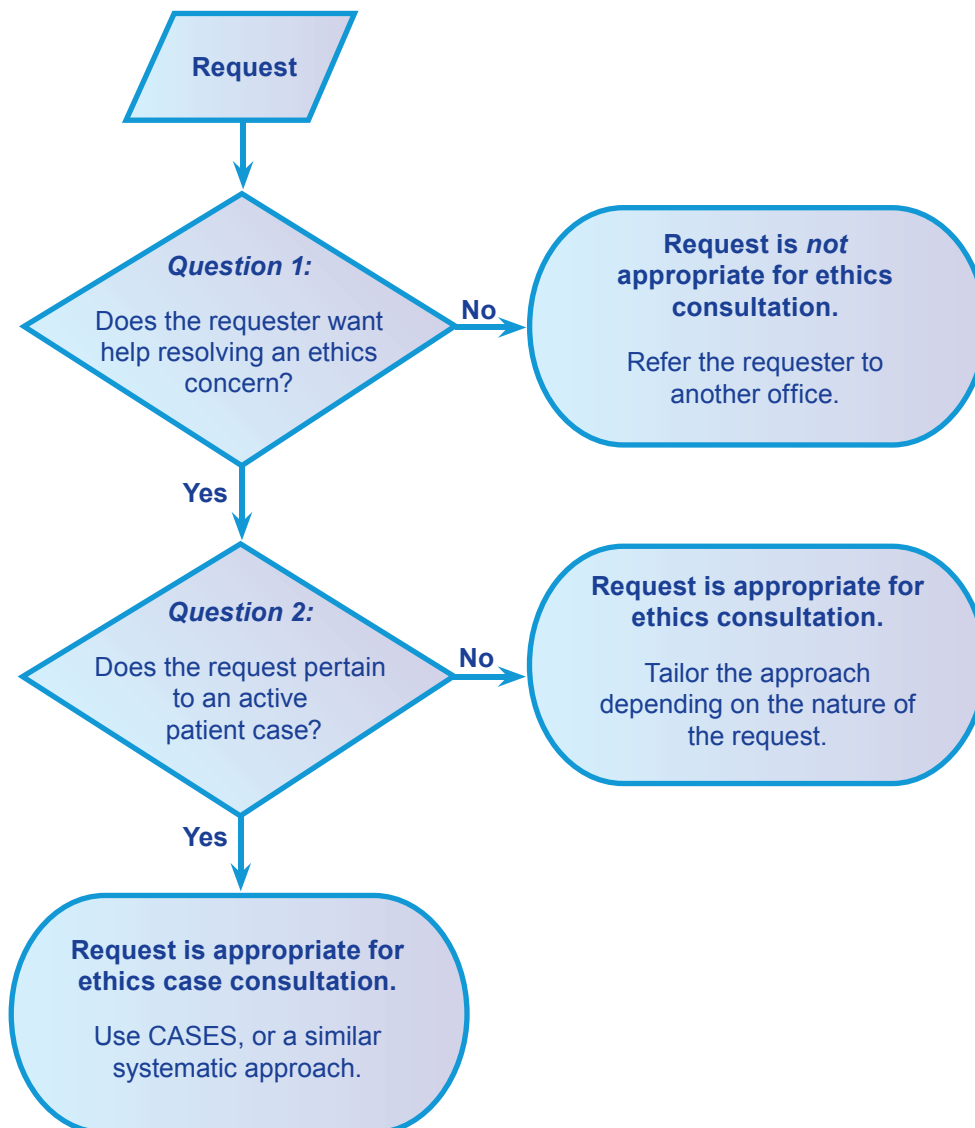
Some questions relating to a patient case may seem straightforward, and too simple to warrant use of the CASES process. Even these should be addressed systematically and

comprehensively, because ethics cases are often more complex than they are initially presented or perceived to be. For example, the information presented by the requester may not be complete or accurate, and may change once additional information is collected.

Or other parties involved in the case may have morally relevant perspectives that are not communicated by the requester but ought to be considered. For reasons like these, ethics case consultations should not be handled through an “informal” or “curbside” approach. *(Note: When ethics consultants are asked to comment informally on a clinical ethics question, they should make it clear that they can only respond in general terms and absolutely cannot give recommendations about a specific patient case without completing a formal consultation process.)*

This decision rule is depicted schematically in **Figure 1**.

**Figure 1. Is the request appropriate for ethics case consultation?**



### ***Obtain preliminary information from the requester***

Having verified that the request is appropriate for the CASES approach, it is important to obtain information that will facilitate planning the next steps of the consultation process.

Consultants should obtain the following basic information:

- Requester's contact information and title
- Urgency of request
- Brief description of the case and the ethics concern as the requester understands them
- Requester's role vis-à-vis the case (e.g., attending physician, family member, administrator)
- Steps already taken to resolve the ethics concern
- Type of assistance desired (e.g., forum for discussion, conflict resolution, policy interpretation)

Once this information is obtained, the consultant should determine, in a preliminary way, what consultation model best suits the request (see Part I, "What Models May Be Used to Perform Ethics Consultation?"), which personnel can best address the concerns it raises, and what steps should be taken next.

### ***Establish realistic expectations about the consultation process***

It is important for the consultant to provide a concise, clear description of the ethics consultation process and how it helps resolve ethics concerns. This is particularly important for requesters who are seeking ethics case consultation for the first time as it can help correct misconceptions, for instance about the time frame or nature of the response that will be provided. The information can be communicated orally, electronically, or in print form. The information should include a clear statement of the goals of the ethics consultation process. Consultants should also attempt to identify and correct any misconceptions the requester may have about the ethics consultant's role. For instance, the ethics consultation service does not take over decision making in the case, nor does it automatically "rubber-stamp" the position of the health care team. Finally, consultants should take time to explain how their role as an ethics consultant differs from other roles they play in the organization. For example, an ethics consultant who is also a medical specialist may be qualified to offer technical advice about medical treatments, but such advice would generally not be considered part of the ethics consultation process.

### ***Formulate the ethics question***

Formulating the ethics question can be the single most difficult, yet most important part of ethics case consultation. Formulating the ethics question in a clear way allows all participants to focus on the central ethics concern and to work efficiently toward a solution. Formulating the ethics question poorly or imprecisely can sidetrack or derail the consultation process. In addition, in some cases, the process of clarifying the ethics question may lead to the realization that the situation is not appropriate for ethics case consultation after all. For these reasons, ethics consultants should formulate the ethics

question early in the process and examine this formulation again at a later stage, once all the relevant information has been assembled.

In an ethics case consultation, an **ethics question** asks which decisions or actions are ethically justifiable given an ethics concern. The initial formulation of the question should state the question in a way that is helpful to those who will be involved in resolving the case. It should not emphasize abstract concepts, or attempt to display the consultant's erudition. At the risk of reducing important issues in ethics to a formula, we suggest that an ethics question be constructed as shown in **Figure 2**.

**Figure 2. Formulating an ethics question**

**Use either of the following structures to formulate an ethics question:**

Given \_\_\_\_\_, what decisions or actions are ethically justifiable?  
uncertainty or conflict about values

Given \_\_\_\_\_, is it ethically justifiable to \_\_\_\_\_?  
uncertainty or conflict about values      decision or action

In some ethics case consultations there may be more than one ethics concern. When this occurs, it may be necessary to formulate more than one ethics question. At each step in the consultation process, all relevant ethics questions should be considered. Sometimes, as a consultation unfolds, the ethics question may change, and/or additional questions may emerge. Nonetheless, formulating the central ethics question at the outset is essential as it helps to focus subsequent steps.

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Consider a case in which the surrogate for a patient who lacks decision-making capacity asks that mechanical ventilation be stopped. The health care team wishes to continue providing this treatment because they believe the patient might recover the ability to breathe on his own. They ask the ethics consultation service whether they should discontinue mechanical ventilation.

The ethics question in this case can be stated as:

Given the conflict between the surrogate's right to make health care decisions on behalf of the patient and the health care providers' obligation to act in the best interests of the patient, what decisions or actions are ethically justifiable?

Or

Given the conflict between the surrogate's right to make health care decisions on behalf of the patient and the health care providers' obligation to act in the best interests of the patient, is it ethically justifiable to withdraw mechanical ventilation?

Although the concern could be stated as a tension between the ethical principles of autonomy and beneficence, that formulation may be too general and abstract to be helpful to the participants at this stage.





## Step 2: Assemble the Relevant Information

The second step of the CASES approach is to assemble information about the case. In this step, consultants solicit data from multiple sources to build a more comprehensive picture of the case.



### **ASSEMBLE** the Relevant Information

*Consider the types of information needed  
Identify the appropriate sources of information  
Gather information systematically from each source  
Summarize the case and the ethics question*

### **Consider the types of information needed**

The CASES approach builds on the work of Jonsen, Siegler, and Winslade in defining topics that should be reviewed in every ethics case consultation.<sup>16</sup> Our experience with ethics consultation suggests a somewhat different formulation of information and we reframe Jonsen and colleagues' "medical indications," "patient preferences," "quality of life," and "contextual features" into three slightly different categories ("medical facts," "patient's preferences and interests," and "other parties' preferences and interests") and add "ethics knowledge" as a fourth category of information that needs to be reviewed for each ethics case consultation.

**Medical facts.** First, ethics consultants must be well informed about the medical facts of a patient case. Indeed, some cases can be resolved merely by clearing up factual misunderstandings among patients, families, and members of the health care team. When gathering medical facts, consultants who have clinical training may be at an advantage relative to their nonclinical colleagues, since they can apply their medical knowledge to critically assess the accuracy and adequacy of the information. In general, the more limited the consultant's medical knowledge relevant to the case, the more effort is needed to collect, understand, and confirm the medical facts.

**Patient's preferences and interests.** Ethics consultants also need information about the patient's preferences, values, and perceived needs and interests as they pertain to the patient's clinical circumstances. To the extent possible, this information should be obtained directly from the patient, although other parties can add important insights to help put the patient's perspectives into context. For patients who lack decision-making capacity, information about the patient's values and preferences should be obtained by examining advance directive documents and notes in the health record, speaking to the patient's surrogate decision maker, and interviewing other people, such as relatives, friends, and health care providers, who might have relevant information to share (for example, about the patient's cultural values and religious beliefs). This information from and about the patient should be used to frame conversations about the appropriate goals of care.

**Other parties' preferences and interests.** Next, ethics consultants need to collect information about other interests surrounding the case. Family, friends, and other stakeholders who may be affected by the outcome of the case deserve to have their views and preferences considered. For example, the family may have concerns about financial matters or caregiver burdens; health care professionals may have issues related

to professional integrity; the health care organization may have interests in protecting its reputation and pleasing outside stakeholders, such as Congress, unions, and veterans service organizations; and there may be public health concerns or other matters that affect the broader community. Also, appreciating the diverse and potentially competing perspectives surrounding a case enriches the consultant's grasp of the complexities involved, and often leads to new insights and ideas.

**Ethics knowledge.** Finally, in response to a consultation request, it is important for the ethics consultant or team to draw upon ethics knowledge relevant to the case, also known as “best thinking.”<sup>17</sup> Ethics knowledge can be gleaned, for example, from codes of ethics, ethics standards and guidelines, consensus statements, scholarly publications, precedent cases, and applicable institutional policy and law. *For novice consultants, the “Assemble” step should always involve at least some reading about the topic*, and often should include a literature review. For experienced consultants, the effort they need to devote to gathering ethics knowledge will vary; for example, if the consultant has in-depth training and previous experience directly relevant to the case at hand, he or she may not need to conduct a new literature review, but simply reflect on what ethics knowledge is relevant to the case.

Ethics consultants should be familiar with a range of ethics-related journals and texts, know how to perform computer searches, and make good use of these skills to research a case when needed. Although reviewing the literature may seem daunting at first, as consultants gain experience they become more familiar with the topics and how to access information efficiently. For less experienced consultants, discussion with a more experienced consultant at this stage is another important resource.

Each ethics consultation service needs to have basic legal knowledge and ready access to legal expertise. Although the ethics consultation service should not provide legal advice, consultants must appreciate the legal implications of cases, and have a sense for when it is appropriate to seek advice from legal counsel. An ethics consultant should also thoroughly understand a range of VHA policies, particularly those relating to informed consent, advance care planning, privacy and confidentiality, end-of-life care, and do-not-resuscitate (DNR) orders.

Finally, ethics consultants should build and sustain a network of outside contacts who can provide specialized ethics expertise as needed. Ethics experts may be found at other VHA facilities, and within universities or ethics centers. For especially difficult or challenging VHA cases, the National Center for Ethics in Health Care's consultation service can be a useful resource.†

### ***Identify the appropriate sources of information***

**Patient.** In ethics case consultation, failure to meet the patient can lead to serious quality problems. *A face-to-face visit with the patient is desirable in all cases, except those in which the patient's perspective is not ethically relevant to resolving the concern.* For example, if a consultation is focused on a physician-nurse disagreement over whether a particular patient should be offered the option of feeding tube withdrawal, the consultation may proceed without the patient's involvement.

†VA employees may access the National Center for Ethics in Health Care's consultation service by email at [vhaethics@va.gov](mailto:vhaethics@va.gov).

Reports that the patient is not interactive or responsive should not dissuade consultants from visiting the patient. Direct observation alone can enrich the consultant's understanding of patient's situation and reveal new information that was not readily available from other sources (e.g., the patient appears to enjoy television, or appears in distress). In addition, patients who lack decision-making capacity may still be able to communicate in ways that help inform decisions that others must make for them. For example, even patients who are quite cognitively impaired may be able to indicate their current experience of pain, or their aversion to a feeding tube.

Unfortunately, face-to-face contact with the patient is not always a realistic option, as when the consultant and the patient are separated geographically (e.g., the patient is receiving home care). Whenever interviewing the patient is not a realistic option, the consultant must take extra steps to assure that the patient's status, preferences, values, and needs are accurately understood.

**Health record.** A careful review of the patient's health record is a necessary step in all ethics case consultations. Ethics consultants should not rely on the requester's brief summary of the patient's case, but should *look to the health record to develop a detailed understanding of the clinical situation*. In addition to medical facts, the patient's record can reveal emotional reactions, judgments, and attitudes that may prove helpful in understanding and resolving conflicts. For instance, the health record may indicate that staff members harbor sad feelings about the imminent death from cancer of a young patient. These powerful feelings may help explain a reluctance to limit life-sustaining treatment.

In addition to examining the patient's health record, ethics consultants should seek out other relevant documents that may not yet be in the record, such as advance directives, court papers establishing guardianship, or health records from other providers.

*Ethics consultants with access to health records do not need specific authorization to access a particular patient's health record in response to a consultation request.* Under the Health Insurance Portability and Accountability Act (HIPAA), health care providers may access patients' records for the purpose of treatment, defined as "the provision, coordination, or management of health care and related services for an individual by one or more health care providers, including consultation between providers regarding a patient and a referral of a patient by one provider to another," or for the purpose of health care operations.<sup>18</sup> Thus under HIPAA ethics consultation on an active patient case is considered part of the treatment process.

Although ethics consultants are authorized to view health records, when accessing patients' medical information they must comply with all relevant privacy policies and regulations.<sup>19, 20</sup> For example, ethics consultants must access only the information they need to perform their function. Consultants should receive appropriate privacy training and be granted access to health records in accordance with local policy. If individuals who are not VA employees participate in any aspect of ethics consultation, the consultation service should seek guidance from the local privacy officer and/or Regional Counsel to assure that these individuals meet all applicable legal requirements. In most circumstances this will involve requiring specific authorization granting these individuals access to identifiable patient information or appointing them to the staff per local policy (e.g., in volunteer or without compensation status).<sup>21</sup> Non-VA consultants should be required to complete privacy training and to comply fully with all relevant privacy policies and regulations.<sup>19</sup>



**Staff.** The ethics consultant should interview key staff members who may have important information or views to share. This often includes the responsible attending physician, house staff, the primary nurse, and the patient's primary care provider (if different from the attending physician), as well as specialists or allied health providers critical to the case. Interviews with staff can be especially helpful in clarifying medical facts, treatment alternatives, and prognosis. For example, a dietitian may be the best person to speak to about options for patients who cannot take food by mouth. A social worker may have invaluable information about placement and discharge planning. In addition, health care workers' personal interests and perspectives are often central to the case, especially when the case involves a conflict between the patient or surrogate and the health care team.

**Family members and friends.** It is also important in many cases to interview other people familiar with the patient, such as close relatives and friends. For patients who retain decision-making capacity, family and friends may supply helpful contextual information, such as insights into patients' motivations, or explanations about their religious beliefs. When contacting family members or friends, consultants must be careful to respect patients' privacy in accordance with VA policy and the law.

When a patient lacks decision-making capacity, responsibility for health care decisions falls to another person authorized to make decisions on the patient's behalf—the surrogate decision maker. The ethics consultant will need to interview the authorized surrogate to obtain information and to clarify for the surrogate his or her responsibilities as they apply to the case. It is often useful to supplement the information provided by the surrogate with information from other family members or friends—this is especially important when the surrogate does not seem to be adequately representing the patient's preferences or values or there is conflict within the family.

### ***Gather information systematically from each source***

**Collect sufficient information.** Ethics consultants should gather data from these sources in a thorough and systematic manner. The content and depth of information required will vary depending on the case at hand. For example, if the consultation is about a spouse who allegedly refuses to honor a patient's advance directive, information gathering should focus on confirming that the patient lacks decision-making capacity, establishing that the spouse is the authorized surrogate, ascertaining the patient's preferences and values and interpreting how those preferences apply to the current situation, as well as clarifying the spouse's position and understanding his or her rationale.

**Verify the accuracy of information.** The quality of an ethics case consultation depends on the accuracy of the information collected, thus consultants should assure that the information they rely on is accurate. Whenever possible, *information should be collected directly from the source*, rather than through secondhand reports. For example, if an advance directive is ethically relevant to the case, the document itself should be examined directly. It would not be appropriate for the consultant, or team, to rely on a description of its content. Similarly, if a family member's perspective is important, that person should be interviewed personally. In addition, whenever possible critical information should be independently verified—that is, collected from more than one source. For instance, in the case of a patient who lacks decision-making capacity, if two different people were to describe the patient's preferences in similar terms, this would lend credence and weight to that information.

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Suppose a nephrologist states that dialysis is futile for a particular patient.

She might mean by this:

- a. *It is not medically possible to dialyze the patient safely and effectively, or*
- b. *While dialysis could be used, it is not “appropriate” based on her belief that the potential benefits of dialysis are minimal given the patient’s cognitive impairments.*

Upon hearing the word “futile,” ethics consultants should ask questions to determine exactly what the speaker means, such as:

- *Is the patient going to die?*
- *If so, how long is the patient expected to survive—a week? a month? a year?*
- *Is that estimate based on specific data, or on general clinical judgment?*
- *Is there any possibility that the patient will improve enough to leave the ICU? to be discharged? to live independently?*

It may also be necessary to ask similar questions to clarify the recommended treatment plan and the possible alternatives.

Other potentially value-laden terms that need to be critically assessed include “terminally ill,” “noncompliant,” “quality of life,” and “poor prognosis.”

**Distinguish facts from value judgments.** *Consultants should also be careful to distinguish facts from value judgments, since case descriptions often reflect a combination of objective knowledge and opinions.*

**Handle interactions professionally.** When approaching patients, families, and staff members for interviews, consultants should offer not only a personal introduction, but also a succinct description of the goals of ethics consultation and the CASES approach. For example, when the consultant first meets a patient who is not familiar with ethics case consultation, the consultant might explain that her job is to help people work through difficult decisions by listening to what everyone thinks and applying ethics knowledge and experience to help the decision maker decide the best thing to do. It is also helpful to explain the ethics question in the case, as well as the interviewee’s role in the consultation process. Consultants should make it clear that they will attempt to protect the rights and interests of all involved in the case.

Participation in ethics consultation is always voluntary, and anyone, including the patient or surrogate, may choose not to participate. Because ethics consultation is not a clinical treatment or procedure, it is not necessary to obtain explicit informed consent. Nonetheless, if a patient or surrogate objects to the ethics consultation, consultants should seriously consider whether it is in the best interests of the patient or the organization to proceed without the patient’s permission.

Prior to visiting the patient, the consultant should notify the patient’s attending physician. Notification is important for two reasons: first, as a courtesy, and second, to determine whether there are legitimate medical considerations that should influence the consultant’s

plans. For example, in the case of a patient suffering from extreme paranoia, the patient's physician may advise the consultant to postpone interviewing the patient or make suggestions about how to avoid aggravating the patient's condition. However, the attending physician may not use his or her authority to block a consultation that is initiated by another person with standing in the case, since this would effectively deny requesters access to the institutional resource designed to help them with their ethics concerns.

In their interactions with participants, ethics consultants should encourage all parties to participate and also strive to remain empathically neutral. Even in the most highly charged situations, ethics consultants should serve as models of respectful professional behavior.

***Summarize the case and the ethics question***

Once information has been assembled and verified, it should be summarized for the benefit of everyone involved in resolving the case. The consultant may communicate the information in one-on-one conversations, in meetings, and/or in writing. The summary must include all of the important information, yet be clear and succinct. Consultants should be careful to report information from various sources respectfully, and should attempt to reconcile contradictory information. The summary should describe the uncertainty or conflict, not contribute to it. Sometimes a clear and thorough summary is all that is needed to resolve the ethics question and the underlying ethics concern.

After summarizing the relevant case information, the consultant should reexamine and clarify the central ethics question. Often this requires reformulating the question by repeating the procedure described under Step 1, "Clarify the Consultation Request."

### Step 3: Synthesize the Information

The third step in the CASES approach requires the consultant to synthesize the information about the case in an effort to address the ethics concern.

## S

### SYNTHESIZE the Information

*Determine whether a formal meeting is needed*  
*Engage in ethical analysis*  
*Identify the ethically appropriate decision maker*  
*Facilitate moral deliberation about ethically justifiable options*

#### ***Determine whether a formal meeting is needed***

After assembling relevant information about the case, it is important for the ethics consultant to help others process the information for themselves, in an effort to resolve any remaining uncertainty or conflict about values. Sometimes the best way to accomplish this synthesis step is to gather the key parties for a formal meeting facilitated by the ethics consultant. We find that formal meetings are especially useful when the patient, surrogate, or other parties are not confident that their interests or views have been accurately represented or fully taken into account, when the parties are having trouble understanding each others' points of view, or when there are many different parties involved.

Some ethics consultants convene a formal meeting in every case and in fact use the meeting format to gather basic information. We find several problems with this approach. In our experience, a formal meeting is not always necessary. Formal meetings can be logistically difficult and time consuming to arrange, which can delay the consultation process. In addition, such meetings consume a large number of person-hours, making them inefficient compared to other alternatives. Some people are uncomfortable speaking in front of a group; this is especially a problem for patients and family members, who may be intimidated by the presence of multiple representatives from the facility. If consultants rely on formal meetings as their primary means for gathering information, key pieces of information may not be available during the meeting, and there is little opportunity to verify that the information presented is accurate. In addition, consultants who enter a formal meeting "cold" or who fail to gather sufficient information in advance may find themselves poorly prepared to discuss the relevant ethics knowledge in depth. For these reasons, we recommend that the consultant assemble most if not all of the relevant information before determining whether to convene a formal meeting.

If a formal meeting is needed, it may be arranged by the consultant or by a member of the treatment team. Before the meeting, the consultant should, if possible, communicate with each of the key participants. A prior interview can help the patient or the surrogate feel safer and more comfortable talking openly during the meeting. The consultant should also make sure to review the relevant ethics knowledge in advance.

Once the group is assembled, the consultant should begin with introductions, explain the goals of ethics consultation and the role of the ethics consultant, and establish clear expectations and ground rules for the meeting. Ground rules might include asking parties to treat each other with respect despite whatever strong feelings they may have, for example, by allowing each other to talk without interruption. When an ethics consultation is rife with conflict, formal meetings can be especially challenging. In such circumstances the success of the consultation may hinge on expert facilitation or mediation skills.<sup>14</sup>

Dubler and Liebman<sup>14</sup> suggest that mediation training offers a sound framework to attain the process and interpersonal skills needed for effective bioethics consultation. They propose a specific method called “bioethics mediation,” which combines the perspective of ethics consultation with the tools and techniques of mediation and dispute resolution in order to facilitate a “principled resolution” to complex conflicts in the health care setting.

In any formal meeting, an important role for the ethics consultant is to “level the playing field”—that is, to help ensure that all parties involved, especially those who hold less power in the system, have an equal opportunity to express their views. The consultant should also help the parties clarify and express their values as they apply to the case. Finally, a formal meeting can also be used to identify the ethically appropriate decision maker and the morally acceptable options.

### ***Engage in ethical analysis***

Whether or not a formal meeting is held, the ethics consultant needs to engage in ethical analysis by applying the relevant ethics knowledge to the case-specific information and the ethics question. This process involves rigorous, critical thinking to develop arguments and counterarguments based on consideration of principles, values, rights, obligations, analogous cases, and expected consequences. Ethical analysis is almost always enriched by discussion with and critique by other experienced ethics consultants. Another important part of ethical analysis is clarifying the relevant ethics concepts for the parties involved.

The ability to perform ethical analysis is one of the most difficult yet most important proficiencies an ethics consultant must master. Proficiency in ethical analysis requires a foundation of strong analytic skills, augmented by reading, study, and supervised practical experience over time. Ethics consultants should not rely exclusively on a single approach to ethical analysis; rather, they should draw on a broad repertoire of approaches and incorporate elements of multiple approaches as appropriate when analyzing a single case. Familiarity with a range of theoretical perspectives provides the consultant with a variety of different lenses to “combine and shift” in order to unpack tough ethics questions.<sup>22</sup>

Common approaches to ethical analysis that may be employed in ethics case consultation are summarized in **Figure 3**.



### Figure 3. Approaches to Ethical Analysis

#### **Principlism**

In their widely cited *Principles of Biomedical Ethics*,<sup>23</sup> Beauchamp and Childress lay out what is known as the “principlist” approach to ethical analysis. They describe four principles—autonomy, beneficence, non-maleficence, and justice—that many clinical ethics consultants explicitly draw on when they analyze a case. Ethics consultants should be familiar with these principles, but must be cautious not to use them inappropriately. In particular, inexperienced consultants without specific training in philosophy or humanities may be prone to overuse and or apply the principles in an overly simplistic manner. Labeling the problem in these terms and relying on this approach exclusively to reach a conclusion is not advisable. As Beauchamp and Childress themselves point out, the principles are not sufficiently detailed to provide practical guidance for case consultation, and relying on them as the primary method of ethical analysis should be avoided. For example, knowing that autonomy is in conflict with beneficence does not lead directly to practical recommendations in a particular case.

#### **Casuistry**

Other ethics consultants emphasize a “casuist” approach. Casuistry is a practical, as opposed to theoretical, approach to ethical decision making that attempts to determine the best response to a moral problem by drawing conclusions based on parallels with accepted responses to similar, “paradigmatic” cases. Jonsen, Siegler, and Winslade employ a casuist approach in their system of clinical ethics case consultation. Their widely read book, *Clinical Ethics*,<sup>16</sup> proposes a four-part system in which the central ethics question is analyzed in reference to medical indications, patient preferences, quality of life, and the distinctive contextual features of the case. These authors prompt consultants to include a range of factors in their ethical analysis, such as treatment goals and patient decision-making capacity. Caution should be employed when using casuistry as the sole method of ethical analysis because at times “paradigmatic” cases can conflict or be applied in a general way to circumstances that differ in subtle but ethically salient ways from the paradigm case.<sup>14</sup>

#### **Other Approaches**

Other important approaches to ethical analysis exist, including feminist ethics,<sup>24, 25</sup> the deductivist “moral rules” approach,<sup>26</sup> and narrative ethics.<sup>27, 28</sup> Like the approaches detailed above, all have specific advantages and disadvantages that might make them more or less applicable to a particular case.

### **Identify the ethically appropriate decision maker**

A surprising number of ethics case consultations can be resolved simply by clarifying who the rightful decision maker is in the particular circumstances. A number of subtle issues may make it difficult to identify who is the ethically appropriate decision maker (or, at times, who are the appropriate decision makers), so the ethics consultant should approach this matter carefully. A patient who has **decision-making capacity** has the right to accept or reject any treatment or procedure that is offered, and this decision may not be overruled.

When a patient lacks decision-making capacity, a search should be made for an authorized **surrogate**. Consultants may need to help staff determine who is authorized to serve as surrogate under VA policy, and to explain the obligations and limits of surrogacy. VA policy not only establishes a priority hierarchy of authorized surrogates, but also mandates that such surrogates base their decisions on the patient's preferences and values if they are known, and if not, on the patient's best interests.<sup>29</sup> Thus the consultant should *work closely with the surrogate to determine the patient's relevant preferences and how they apply to the current situation*. For example, the consultant might ask the surrogate, "If your husband were able to talk to us, what would he say?"

*The decisions of a willing and able surrogate who is authorized to serve should generally be honored* even if others seem to have a closer relationship with the patient. Consultants should try to support surrogates in the decision-making process. They should resist the temptation to second guess an authorized surrogate's decision, for example, by speculating on a potential conflict of interest, because most patients want their surrogate to make decisions for them. In fact, patients often would want this even if the surrogate were to make a decision that is different from one they would have made themselves.<sup>30, 31</sup> Only in rare cases when a surrogate insists on a decision that is clearly contrary to the patient's wishes or best interests should it be necessary to disqualify a surrogate. When the incapacitated patient has *no authorized surrogate*, the ethics consultant should facilitate the process described in VA policy.

Since identification of the ethically appropriate decision maker often hinges on the question of the patient's capacity to make health care decisions, *ethics consultants need to thoroughly understand the concept of decision-making capacity and how it is determined*.<sup>32</sup> Though ethics consultants do not need to be able to assess decision-making capacity themselves, they should be able to determine whether capacity has been appropriately assessed. If a patient's observed capacity seems to be at odds with what is described in the record, the consultant should address the discrepancy with the responsible health care provider(s).

It should be noted that *the patient's (or surrogate's) primacy as the ethically appropriate decision maker is not absolute*. Society does not recognize a right for patients to receive any treatment they (or their surrogates) demand. Rather, responsibility for determining which treatment options are medically acceptable and may be offered—and therefore what options a patient may accept or refuse—rests with **health care professionals**. That is, a patient's decision to accept or refuse a treatment or procedure rests on the clinician's prior professional judgment about what particular treatments or procedures are consistent with sound medical practice given the patient's specific clinical circumstances.

For example, in an ethics case consultation that revolves around a patient's request for an unconventional treatment, the critical decision in the case is whether the treatment should

or should not be provided. That decision rests on the exercise of professional judgment, and thus the ethically appropriate decision maker is the treating clinician. His or her decision will involve several considerations, including the probable risks and benefits of the specific treatment given the patient's clinical situation. If, in the judgment of the treating clinician, the requested treatment is unlikely to cause harm, he or she may decide to honor the patient's request, even though the intervention falls outside the standard of care in the professional community. Or, the treating clinician might decide not to honor the patient's request, but instead to refer the patient to another clinician who is willing to provide the treatment. Either option could be ethically justifiable. Of course, clinicians must be careful not to abuse their authority by usurping decisions that rightfully should be made by the patient. For example, a physician may not decline to offer life-sustaining treatment based on his or her personal view that a patient's quality of life is very poor.

For some types of decisions, a health care administrator may be the ethically appropriate decision maker. For example, administrators may legitimately place limits on patient or provider freedoms to protect the health and safety of patients, employees, or the general public. Health care administrators may also need to make tough decisions about how to distribute limited health care resources among programs, services, and patients.

Thus identifying the ethically appropriate decision maker(s) requires careful consideration of the nature of the decisions that need to be made. Consultants should be prepared to sort through and clarify the different judgments that play into a particular situation to identify the critical decision at stake, then identify who should make that decision.

### ***Facilitate moral deliberation about ethically justifiable options***

In the course of assembling and synthesizing information, the ethics consultant learns about different options from participants and other sources. The consultant should also engage in creative problem solving to develop additional options that have not previously been considered. This is particularly important when participants have become polarized around positions that one party or another prefers. A new option that has not previously been explored may offer a neutral and therefore acceptable solution.

Once the options have been offered, the ethics consultant should reiterate who should make the critical decision(s) in the case, then facilitate moral deliberation to help the decision maker(s) determine which option is best. This is known as "ethics facilitation," and—in contrast to the "authoritarian approach" in which the ethics consultant recommends a single course of action as the most ethically preferable—is the approach recommended in the ASBH *Core Competencies* report.<sup>9</sup> The consultant strives to create what Walker calls "space for moral reflection,"<sup>33</sup> thereby helping to build shared understandings. This process respects the rights of decision makers to decide, within ethically justifiable limits, in accordance with their individual values.

Not all options are ethically justifiable, however. A proposed option might, for example, violate an important tenet of health care ethics, such as a patient's right to refuse treatment. In such cases, the consultant should help the decision maker(s) understand how societal values, institutional policies, and/or legal standards relate to the proposed option, citing specific sources to support the claim that a particular option should be rejected. To avoid usurping the authority of the moral decision maker, ethics consultants must be careful to clearly differentiate between claims about what is ethically justifiable, and judgments that



reflect the consultant's personal values. If, at the end of this discussion, the decision maker continues to insist on an option that the ethics consultant deems ethically unjustifiable, the consultant should bring this to the attention of a higher institutional authority who is in a position to affect the outcome. For example, if the attending physician insists on providing blood products to a Jehovah's Witness patient despite the patient or surrogate's refusal of treatment, the consultant should bring this to the attention of the service chief.

The process of deliberation should yield a specific recommendation and a concrete plan of action. If all parties concur about how to proceed, the recommendation and plan will focus on implementing the agreed on decision. If, however, no consensus is reached, the consultant should make recommendations on how to alleviate any residual ethics concerns and articulate a specific plan regarding next steps.

## Step 4: Explain the Synthesis

The next step in the CASES approach requires the ethics consultant to explain the synthesis to others involved in the case. This step helps to assure that ethics concerns are resolved, and it often serves an educational purpose as well. The synthesis should be communicated to key participants directly, and documented in both the health record and in consultation service records.

# E

## **EXPLAIN** the Synthesis

- Communicate the synthesis to key participants*
- Provide additional resources*
- Document the consultation in the health record*
- Document the consultation in consultation service records*

### ***Communicate the synthesis to key participants***

Communicating the synthesis and reaching closure with participants is crucial to success. The ethics consultant should contact the requester and, if appropriate, the patient or surrogate and other key participants in the consultation process.

Ethics consultants should describe what transpired, as well as the resolution and any further recommendations or plans. This gives participants an opportunity to discuss aspects of the case privately with the consultant, which can help resolve any remaining concerns. The ethics consultant should indicate his or her willingness to continue working with participants, including those who disagree with the plan. In some cases, the consultant may discover that significant factors were overlooked in the proposed plan and that it must be revisited. In any event, the consultant should continue to provide information and support. In addition, the consultant should consider whether anyone not involved in the consultation service should be notified of the case (e.g., the service chief).

### ***Provide additional resources***

Educating staff, patients, and families is an important part of the ethics case consultation process. For this reason, ethics consultants should reinforce and supplement their explanation of the synthesis by providing resources that participants can use to find more information. This could include providing copies of articles, book chapters, or other publications that might help participants understand the ethical analysis, or web links to additional information about the topic. Over time, ethics consultants should compile a collection of user-friendly resources to provide to participants, including materials that are specifically targeted to patients and families.

### **Document the consultation in the health record**

Documenting the consultation is another important aspect of communicating the synthesis. All ethics case consultations should be documented in the health record, except when the patient's involvement was not ethically relevant. For example, if a nurse wishes to be reassigned for reasons of conscience, the patient would not be invited to participate in the consultation and it would not be necessary to document this in the health record. (See also "Identify the appropriate sources of information" in Step 2, "Assemble the Relevant Information.")

Good documentation in the health record not only communicates information to involved staff, it also promotes accountability and transparency, and documentation for legal purposes. Because this documentation may be read by many staff as well as by the patient or the patient's representative, it should be professional in tone. Consultants should avoid generalizations and jargon, and all information included should be relevant to the specific patient case.

The ethics case consultation note in the health record should normally contain the following elements:

- Name and role of the requester
- Date and time of the request
- Name(s) of consultant(s)
- Brief description of the circumstances, including the ethics concern
- Ethics question
- Sources and brief summary of the relevant information, including:
  - Medical facts, patient's preferences and interests, other parties' preferences and interests
  - Explanation of patient's decision-making capacity
  - Information about patient's advance directive, if applicable
  - Information about authorized surrogate, if applicable
  - Ethics knowledge
- Description of any formal meetings held
- Summary of ethical analysis
- Identification of the ethically appropriate decision maker(s)
- Options considered, and whether they were deemed ethically justifiable
- Explanation of whether consensus was reached
- Recommendations and action plan(s)

**Appendix 4** provides a sample ethics case consultation summary and template.

***Document the consultation in consultation service records***

Regardless of whether the ethics consultation was documented in the health record it should always be documented in the consultation service's internal records. These records are useful for performance improvement, informing future consultations, legal documentation, and workload tracking.

The consultation service records should include all health record notes, as well as additional information that does not necessarily belong in the health record, such as:

- Communications among consultants
- Sensitive information, such as comments on the power dynamics observed
- Logistical details, such as scheduled appointments
- Notes and references relating to the sources of ethics knowledge
- Documentation of Step 5, “Support the Consultation Process” (below)

## Step 5: Support the Consultation Process

After the synthesis has been explained and documented, the final step in the CASES approach is to support the overall process of ethics case consultation. The consultant should:

### SUPPORT the Consultation Process

S

*Follow up with participants*  
*Evaluate the consultation*  
*Adjust the consultation process*  
*Identify underlying systems issues*

### ***Follow up with participants***

At some interval after the completion of the ethics case consultation, consultants should follow up with the requester and/or other key participants. Contact with these individuals enables the consultant to determine if any new ethics concerns have emerged that need to be addressed and learn the outcome of the case, including whether the consultant's recommendations (if any) were followed.

By following up in this fashion, the ethics consultant can see whether the recommended plan actually helped resolve the ethics concern. If the participants followed the plan but the ethics concern was never resolved, the consultant may need to reactivate the CASES process and offer further support. Even if action is no longer possible (e.g., the patient died), the consultant may still wish to review the case for educational purposes.

If recommendations were not followed, it is important to understand why. For instance, the proposals may have been impractical, requiring time and resources that were not readily available. A participant who disagreed with the suggestions might have undermined the plan, or the patient's circumstances might have changed, so that the proposed solution was no longer applicable. *Consultants can learn a great deal from reviewing cases in which participants did not follow recommendations.* Indeed, the service cannot improve without understanding why the solutions it proposes sometimes fail.

### ***Evaluate the consultation***

Ethics consultation services should also evaluate their consultations more formally with the aim of continuously improving their practices. This evaluation can take several forms. At a minimum, *ethics consultants should always complete a critical self-review* by retrospectively reviewing each case, reflecting on it in conversation with other members of the consultation team, and systematically comparing the actual processes followed to the standards established in this guidance and by the consultation service. Discussion should address opportunities for improvement as well as lessons learned.

In addition, it is important to assess how the ethics consultation service is perceived by systematically surveying the participants in the case. Ideally, someone who was not involved in the consultation process should perform such evaluations in a confidential fashion.

**Appendix 2** provides an assessment tool to gather feedback about the consultation.

Feedback from peers and supervisors can also be invaluable and should be sought. For example, presenting de-identified cases to an ethics committee or executive leadership board can be a learning experience for consultants and committee members alike.

Finally, to further challenge the ethics consultation service to improve, ethics consultants should explore opportunities for external peer review. For example, a consultation service might arrange periodic discussions of de-identified cases with another facility or university affiliate.

### ***Adjust the consultation process***

Depending on the results of the follow-up and evaluation steps described above, the ethics consultation service may need to make systematic changes in its policies and procedures. For example, if follow-up discussions reveal that a participant had a misconception about the consultation process, the team should take steps to assure that its methods for establishing realistic expectations are adequate and consistently deployed. (See “Establish realistic expectations about the consultation process” in Step 1, “Clarify the Consultation Request.”)

### ***Identify underlying systems issues***

Ethics consultation services as described in this document are designed to be reactive and spend most of their effort responding to individual ethics concerns. At times, however, ethics consultations reveal underlying ethics issues that need to be addressed at a systems level—for example, persistent misperceptions among providers about withdrawing feeding tubes that are caused by lack of a clear policy on artificially administered nutrition and hydration.

Thus in addition to an ethics consultation service, facilities need a mechanism for addressing systemic ethics issues. Each consultation should be actively reviewed to determine whether it suggests any underlying systems issues that need to be addressed. In addition, consultation records should be reviewed periodically to look for patterns of recurrent concerns. Significant systems issues should be brought to the attention of the individual or body responsible for handling such concerns on behalf of the institution.



## **Conclusion**

Health care ethics consultation is an important service that helps to assure the quality of patient care. By providing a means through which patients, families, health care professionals, and other staff can address ethics concerns, effective ethics consultation promotes understanding of and respect for patients' preferences, clarification of professional ethical obligations, and adherence to recognized ethical standards. By providing a forum in which staff can grapple with their ethics concerns, effective ethics consultation can also help address the problem of professional "burn out" and help sustain morale. And by visibly engaging in and supporting moral deliberation, the ethics consultation service helps to support an environment in which the link between ethical practice and quality of care is understood and appreciated.

To serve the needs of patients and families, staff, and the institution, ethics consultation must be recognized as an essential activity and appropriately supported. The success of an ethics consultation service depends on several factors: It must be well integrated with other offices and programs within the institution, visibly supported by leadership, and assured the resources (both human and material) that it needs to function effectively. Staff who participate in ethics case consultations must have appropriate expertise and training. Patients and health care professionals within the institution must be aware of the consultation service and what it does and know how to contact it. The service must be clearly situated within the institution's reporting hierarchy, accountable to a designated senior official, and its structure, function, and processes should be formalized in institutional policy. The ethics consultation service must contribute to organizational learning—consultants should regularly share their knowledge and experience with others in the institution. Finally, a successful ethics consultation service must be committed to ongoing evaluation and systematic assessment of its own operations.

Effective ethics consultation also rests on good consultation practice. The CASES approach described in this guidance is intended to help facilities respond appropriately to ethics concerns. By working systematically through the activities of clarifying requests for consultation, assembling relevant information, synthesizing that information to identify morally acceptable solutions, explaining the synthesis to the parties involved in a given ethics case, and supporting the overall consultation process through follow up and evaluation to refine its practices, the ethics consultation service helps to assure that ethics concerns are addressed consistently throughout the facility. And by identifying underlying systems issues that emerge in individual case consultations, or ethics concerns that recur across case consultations, the ethics consultation service can help support a preventive approach to ethics quality.

## Glossary

**CASES:** A systematic, step-by-step process for performing *ethics case consultations* developed by VHA's National Center for Ethics in Health Care.

**Casuistry:** An approach to ethical analysis that attempts to resolve uncertainty or conflict by drawing parallels between the current situation and accepted responses to similar, “paradigmatic” cases. See Jonsen, Siegler, and Winslade, *Clinical Ethics* (2002).

**Decision-making capacity:** A patient's ability to make a given decision about his or her own health care. Clinical determination of decision-making capacity should be made by an appropriately trained health care practitioner.

**End-of-life care:** The domain of health care ethics concerned with decisions about care for patients nearing the end of their lives. It includes decisions about life-sustaining treatments (such as cardiopulmonary resuscitation or artificially administered nutrition and hydration), futility, treatments that hasten death, etc.

**Ethical health care practices:** Decisions or actions in the delivery and/or management of health care that are consistent with widely accepted ethics standards, norms, or expectations for the conduct of health care professionals and organizations. *Note that in this context “ethical” conveys a value judgment—i.e., that a practice is good or desirable; often, however, “ethical” is used simply to mean “of or relating to ethics,” as in the phrase “ethical analysis” referring to analysis that uses ethical principles or theories.*

**Ethical leadership:** Activities on the part of health care leaders to foster an environment and culture that support ethical practices throughout the organization. These include demonstrating that ethics is a priority, communicating clear expectations for ethical practice, practicing ethical decision making, and supporting the facility's local ethics program.

**Ethics:** The discipline that considers what is right or what should be done in the face of uncertainty or conflict about values.

**Ethics case:** An active patient case, i.e., isolated situation involving specific individuals and events, that gives rise to an ethics concern.

**Ethics case consultation:** An *ethics consultation* that pertains to an active patient case.

**Ethics concern:** Uncertainty or conflict about *values*.

**Ethics consultation:** The activities performed by an individual or group on behalf of a health care organization to help patients, providers, and/or other parties resolve *ethics concerns* in a health care setting. These activities typically include consulting about active patient cases (*ethics case consultation*), analyzing hypothetical or historical (nonactive) ethics cases, reviewing documents from a health care ethics perspective, clarifying policy related to health care ethics, and/or answering questions or providing resources on topics in health care ethics. Health care ethics consultation may be performed by an individual ethics consultant, a team of ethics consultants, or an ethics committee.

**Ethics consultation service:** A mechanism within a health care organization that performs *ethics consultation*.

**Ethics issue:** An ongoing situation involving organizational systems and processes that gives rise to an *ethics concern*.

**Ethics quality:** Health care practices, including clinical and managerial practices, are consistent with widely accepted ethics standards, norms, or expectations for the conduct of a health care organization and its staff. Ethics quality encompasses individual and organizational practices at the level of decisions and actions, systems and processes, and environment and culture.

**Ethics question:** A question about which decisions are right or which actions should be taken when there is uncertainty or conflict about values.

**Health care ethics:** The discipline concerned with what is right or what should be done in health care settings, especially with respect to *shared decision making*, *end-of-life care*, *privacy and confidentiality*, *professionalism*, and *resource allocation*.

**IntegratedEthics program:** A local mechanism within a health care organization that improves *ethics quality* in health care by integrating three core functions: *ethics consultation*, *preventive ethics*, and *ethical leadership*.

**Preventive ethics:** Activities performed by an individual or group on behalf of a health care organization to identify, correct, and prevent systemic *ethics issues*.

**Principlism:** A theory-based approach to ethical analysis that emphasizes the four principles of autonomy, beneficence, non-maleficence, and justice. See Beauchamp and Childress, Principles of Biomedical Ethics (2001).

**Privacy and confidentiality:** The domain of health care ethics concerned with protecting patients' personal information. The domain includes matters of patients' control of personal health information, respect for physical privacy and dignity, conditions under which information may/must be shared with third parties, etc.

**Professionalism:** The domain of health care ethics concerned with practitioners' adherence to professional standards of conduct. It includes matters of conflict of interest, truth telling, working with difficult patients, etc.

**Resource allocation:** The domain of health care ethics concerned with fair or just distribution of goods or services. It includes how a facility distributes its resources—including financial resources, materials, and personnel—among programs, services, and patients.

**Shared decision making:** The domain of health care ethics concerned with the process of collaboration between clinician and patient in making health care decisions, to which the clinician contributes his or her knowledge of medicine and the patient his or her values, preferences, and goals for care. The domain includes matters of decision-making capacity, informed consent, surrogate decision makers, advance directives, etc.

**Surrogate:** The individual authorized under VA policy to make health care decisions on behalf of a patient who lacks decision-making capacity.

**Values:** In the health care setting, strongly held beliefs, ideals, principles, or standards that inform ethical decisions or actions.

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## ***Appendices***



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## ***Appendix I***

### **Ethics Consultant Proficiency Assessment Tool**

## **Ethics Consultant Proficiency Assessment Tool †**

### **About the Consultant Proficiency Assessment Tool**

This assessment tool is designed to help individuals who perform health care ethics consultation to assess their proficiency level with respect to the skills and knowledge required to provide competent health care ethics consultation.

### **Using the Results to Create an Individualized Professional Development Plan**

Following completion of the assessment tool, the Ethics Consultation Coordinator should meet with the consultant to review the results and develop an individualized professional development plan to improve upon the consultant's baseline proficiencies. Consultants should have a minimum of a **basic level of skill or knowledge in all assessed items**. (Response categories are shaded on the assessment tool to quickly show the consultant's skill level.)

For consultants who are “not skilled” or “not knowledgeable” in respect to one or more items, an immediate action plan should be developed to bring the consultant to a basic level. For consultants who already have at least basic skills or knowledge on every item, a plan should be designed to help the consultant develop advanced-level skill or knowledge in several of the proficiencies.

### **Identifying Knowledge and Skill Gaps in the Consultation Service**

One of the responsibilities of the Ethics Consultation Coordinator is to ensure that the consultation service as a whole possesses the set of skills and knowledge identified in the *Core Competencies* report. The *Ethics Consultant Proficiency Assessment Tool* can help identify knowledge and skill gaps, especially in areas where at least one member of the ethics consultation service must have advanced skill or knowledge as urged by ASBH. These items are denoted by an \* asterisk on the assessment tool. The *Advanced Proficiencies Tracking Log* can help identify those consultants with advanced expertise.

### **How Often to Use the Consultant Proficiency Assessment Tool**

The tool was designed to help consultants assess change over time and therefore we suggest that consultants repeat the assessment and update their individualized professional development plans on an annual basis. In addition, we encourage the use of the proficiency tool with all consultants who are new to the service. This will help to establish the consultant's baseline proficiencies and to ensure that new consultants receive sufficient mentoring and support.

† This tool is based on a report from the American Society for Bioethics and Humanities entitled *Core Competencies for Health Care Ethics Consultation* (1998).

### Ethics Consultant Proficiency Assessment Tool

The purpose of this tool is to help consultants assess their proficiency with respect to the skills and knowledge required to provide competent health care ethics consultation.

After you complete this tool, you should work with your Ethics Consultation Coordinator to create an individualized professional development plan.

**DIRECTIONS:** Please place an “X” in the box that best describes your present skill or knowledge level.

*Note: ASBH suggests that at least one individual on the consultation service possess advanced skill or knowledge for specific elements. These items are noted with an \* asterisk.*

	Novice	Basic		Advanced	
<b>Interpersonal Skills:</b> skills needed to effectively communicate with others, and to develop positive relationships	Not Skilled	Somewhat Skilled	Skilled	Very Skilled	Expert
<i>Rate your ability to:</i>					
Listen well, and communicate interest, respect, support, and empathy to involved parties*					
Educate involved parties regarding the ethical dimensions of the case					
Elicit the moral views of involved parties in a nonthreatening way*					
Enable involved parties to communicate effectively and be heard by other parties*					
Accurately and respectfully represent the views of involved parties to others when needed*					
Recognize and address barriers to communication*					

	Novice	Basic		Advanced	
	Not Skilled	Somewhat Skilled	Skilled	Very Skilled	Expert
<b>Process Skills:</b> skills needed to facilitate formal and informal meetings, foster moral consensus, and gather, interpret, and document information.					
<b>The next few items assess skill in facilitating formal and informal meetings.</b>					
<i>Rate your ability to:</i>					
Identify key decision makers and other involved parties and include them in discussions					
Set ground rules for formal meetings (e.g., length, participants, purpose and structure, minutes etc.)					
Express and stay within the limits of the ethics consultant's role during meetings					
Create an atmosphere of trust that respects privacy and confidentiality and that allows parties to feel free to express their concerns					
<b>Based on the preceding items</b> , how would you rate your overall ability to facilitate formal and informal meetings?*					
<b>The next few items assess skill in fostering consensus among parties involved in the case.</b>					
<i>Rate your ability to:</i>					
Attend to power imbalances and attempt to level the playing field					
Help individuals critically analyze the values underlying their assumptions, decision(s), and the possible consequences of that decision/ those decisions					
Mediate among competing moral views					
Engage in creative problem solving (i.e., help parties to "think outside of the box").					
Create an atmosphere of trust that respects privacy and confidentiality and that allows parties to feel free to express their concerns					
<b>Based on the preceding items</b> , how would you rate your overall ability to foster consensus among parties involved in the case?*					

	Novice	Basic		Advanced	
	Not Skilled	Somewhat Skilled	Skilled	Very Skilled	Expert
<b>The next few items assess your ability to gather, interpret, and document information.</b> <i>Rate your ability to:</i>					
Gather and interpret information from the health record					
Visit and interview patients in various clinical settings					
Document the consult clearly and accurately in the health record					
Utilize institutional structures and resources to facilitate implementation of the chosen option					
<b>Analytic Skills:</b> skills needed to identify the nature of the value uncertainty or conflict that underlies the need for ethics consultation, and analyze the value uncertainty or conflict that underlies the need for ethics consultation	Not Skilled	Somewhat Skilled	Skilled	Very Skilled	Expert
<b>The next few items assess skill in identifying the nature of the value uncertainty or conflict that underlies the need for ethics consultation.</b> <i>Rate your ability to:</i>					
Gather relevant data (e.g., medical facts, patients' preferences and interests, and other people's preferences and interests)					
Assess the social and interpersonal dynamics of a case (e.g., power relations, racial, ethnic, cultural, and religious differences)					
Distinguish ethical dimensions of the case from other, often overlapping dimensions (e.g., legal, medical, psychiatric)					
Identify various assumptions that involved parties bring to the case (e.g., regarding quality of life, risk taking, hidden agendas)					
Identify, clarify, and distinguish the relevant values of involved parties					
<b>Based on the preceding items,</b> how would you rate your overall ability to identify the nature of the value uncertainty or conflict that underlies the need for ethics consultation?					

	Novice	Basic		Advanced	
<b>The next few items assess skill in analyzing the value uncertainty or conflict that underlies the need for an ethics consultation.</b> <i>Rate your ability to:</i>	Not Skilled	Somewhat Skilled	Skilled	Very Skilled	Expert
Formulate an ethics question based on the facts of the case					
Identify the ethically appropriate decision maker in a particular case (e.g., patient, surrogate, or health care team)					
Access relevant knowledge (e.g., bioethics, law, institutional policy, professional codes, and religious teachings)					
Critically evaluate and apply relevant knowledge to the case (e.g., bioethics, law, institutional policy, professional codes, and religious teachings)					
Clarify relevant ethics concepts (e.g., confidentiality, privacy, informed consent, best interest)					
Identify and explain a range of ethically justifiable options and their consequences					
Evaluate evidence and arguments for and against different options					
Recognize personal limitations and possible areas of conflict between personal moral views and one's role in ethics consultation					
<b>Based on the preceding items, how would you rate your overall ability to analyze the value uncertainty or conflict underlying the need for ethics consultation?*</b>					



	Novice	Basic		Advanced	
Core Knowledge: Moral Reasoning	Not Knowledgeable	Somewhat Knowledgeable	Knowledgeable	Very Knowledgeable	Expert
Rate your knowledge of:					
Moral reasoning and ethics theory, including familiarity with a variety of approaches to ethical analysis (e.g., consequentialist, deontological, principle-based, casuistic)					
Core Knowledge: Common Ethics Issues and Concepts					
Rate your knowledge of:					
Shared decision making (e.g., decision-making capacity, legal competency, informed consent process, surrogate decision makers, advance directives, limits to patient choice)					
End-of-life care (e.g., cardio-pulmonary resuscitation/CPR, life-sustaining treatments, futility, treatments that hasten death, death and postmortem issues)					
Privacy and confidentiality (e.g., patient control of personal health information, exceptions to confidentiality, duty to warn)					
Professionalism (e.g., conflict of interest, truth telling, difficult patients, cultural/religious sensitivity)					
Resource allocation (e.g., systems level or macro-allocation, individual level or micro-allocation)					
Research with human subjects (e.g., informed consent for research, minimal risk, Common Rule)					

	Novice	Basic		Advanced	
Health Care System	Not Knowledgeable	Somewhat Knowledgeable	Knowledgeable	Very Knowledgeable	Expert
<i>Rate your knowledge of:</i>					
Health care systems including, knowledge of managed health care, governmental systems for financing care, etc.					
<b>Clinical Context</b>					
<i>Rate your knowledge of:</i>					
Clinical literacy (e.g., ability to understand medical terms, disease processes, treatments, prognoses, medical decision making, current or emerging technologies, different roles, relationships)					
<b>The Local Health Care Institution</b>					
<i>Rate your knowledge of:</i>					
The local health care facility, including mission statement, organizational structure, range of services, population served, and the perspectives of the local patient and staff population					
Local facility policies related to ethics					
National policies related to ethics					

	Novice	Basic		Advanced	
	Not Knowledgeable	Somewhat Knowledgeable	Knowledgeable	Very Knowledgeable	Expert
<b>Beliefs and Perspectives of the Local Patient and Staff Population</b>					
<i>Rate your knowledge of:</i>					
Beliefs and perspectives that bear on the health care of racial, ethnic, cultural, and religious groups served by the facility					
Resources that can be accessed for understanding and interpreting cultural and faith communities					
<b>Codes of Ethics</b>					
<i>Rate your knowledge of:</i>					
Professional codes of conduct (e.g., medicine, nursing, health care executives) and other ethics guidelines or consensus statements (e.g., Presidents' commissions)					
Guidelines of accrediting organizations related to ethics (e.g., JCAHO)					
<b>Health Law</b>					
<i>Rate your knowledge of:</i>					
Relevant health law (e.g., federal, state, constitutional, statutory, and case law)					

Consultant Name: \_\_\_\_\_

Date Completed: \_\_\_\_\_

## Advanced Proficiency Tracking Log

This log is designed to help the Ethics Consultation Coordinator easily identify which consultants possess the advanced knowledge and skills suggested by the American Society for Bioethics and Humanities.

Listed below are the proficiencies denoted with an \* asterisk on the *Ethics Consultant Proficiency Assessment Tool*.

Advanced Interpersonal Skills	Consultant Name(s)
Listening and communicating interest, respect, support and empathy to involved parties	
Eliciting the moral views of involved parties	
Helping involved parties to communicate effectively and be heard by other parties	
Representing the moral views of involved parties to others when needed	
Recognizing barriers to communication	
<b>Advanced Process Skills</b>	
Facilitating formal and informal meetings	
Fostering consensus	
<b>Advanced Analytic Skills</b>	
Identifying nature of the value uncertainty or conflict underlying the need for ethics consultation	
Analyzing the value uncertainty or conflict underlying the need for ethics consultation	

Advanced Knowledge	Consultant Name(s)
Moral reasoning and ethics theory as it relates to ethics consultation	
Ethics issues and concepts: Shared decision making	
Ethics issues and concepts: End-of-life care	
Ethics issues and concepts: Privacy and confidentiality	
Ethics issues and concepts: Professionalism	
Ethics issues and concepts: Resource allocation	
Ethics issues and concepts: Research	
Health care system	
Clinical context	
Local health care institution	



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## ***Appendix 2***

### **Ethics Consultation Feedback Tool**

### **Ethics Consultation Feedback Tool**

#### **About the Ethics Consultation Feedback Tool**

An important aspect of offering a high quality consultation service is to satisfy the needs and expectations of the customer. The Ethics Consultation Feedback Tool provides a quick and easy means of systematically surveying participants in a case. It has been adapted from an instrument developed for internal use by the Ethics Consultation Service of the National Center for Ethics in Health Care.

#### **How to Use the Ethics Consultation Feedback Tool**

The tool is designed to be completed by any or all of the parties involved in an ethics case consultation, including the requester, clinicians involved in the patient's care, the patient and/or family members, or other individuals who participated in the consultation. Patients and family members bring a unique and important perspective to the consultation service and should not be excluded from participating in the feedback process. At minimum, the person who requested the consultation should be asked to complete the form.

To protect respondents' confidentiality, someone other than the consultant(s) assigned to the case should administer the tool, such as a member of the facility's quality management staff.

#### **Using the Results to Improve the Ethics Consultation Service**

The Ethics Consultation Coordinator should review, summarize, and report the data on an annual or semi-annual basis. Frequencies (number of occurrences) and percents (%) are the easiest and most informative method of summarizing the data. A blank feedback tool can be used to tally or display the summarized data.

In general, the Ethics Consultation Coordinator should prioritize for improvement those items that have a high number or percent of responses concentrated in the fair or poor category. If responses on all items are in the "good," "very good," or "excellent" range, the next improvement goal might be to increase the percentage of responses that are "very good" and "excellent."

Finally, the Ethics Consultation Coordinator should compare summary data by year to evaluate whether improvements are being made or maintained, or if performance is falling off.

### Ethics Consultation Feedback Tool

Recently, you spoke with someone from the Ethics Consultation Service. The job of the service is to help patients, families, and staff work through difficult patient care decisions by listening to what everyone thinks and helping people decide the best thing to do. In order to help improve the Ethics Consultation Service, we ask that you take a few minutes to complete this form.

**DIRECTIONS:** For each of the following statements, please place an “X” in the box that best describes your most recent experience with the Ethics Consultation Service.

Rate the Ethics Consultant(s) on:	Excellent	Very Good	Good	Fair	Poor	Don't Know
Making you feel at ease						
Respecting your opinions						
Being an expert in ethics						
Giving you useful information						
Explaining things well						
Clarifying decisions that had to be made						
Clarifying who is the right person to make the decision(s)						
Describing possible options						
Clearing up any disagreements						
Being easy to get in touch with						
Being timely enough to meet your needs						
Providing a helpful service						

	Excellent	Very Good	Good	Fair	Poor	Don't Know
Overall, my experience with the Ethics Consultation Service was:						

Did the consultation service make any recommendations? Yes No Don't Know (please circle)

If yes, were the recommendations generally followed? Yes No Don't Know

Do you have any comments or suggestions for the Ethics Consultation Service? \_\_\_\_\_

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## ***Appendix 3***

### **Ethics Consultation Pocket Card**

(Note: The following 2 pages can be reproduced back-to-back and folded into a pocket card.)

### Confirm that the request is appropriate for ethics case consultation

- Does the requester want help resolving an ethics concern?
- Does the request pertain to an active patient case?

### Obtain preliminary information from the requester

- Requester's contact information and title
- Urgency of request
- Brief description of the case and the ethics concern
- Requester's role (e.g., attending physician, family member, administrator)
- Steps already taken to resolve the concern
- Type of assistance desired (e.g., forum for discussion, conflict resolution, policy interpretation, moral support)

### Establish realistic expectations about the consultation process

- Describe the case consultation process and its goals (orally or in writing)
- Correct any misconceptions the requester may have

### Formulate the ethics question

- Given [uncertainty or conflict about values], what decisions or actions are ethically justifiable? or  
Given [uncertainty or conflict about values], is it ethically justifiable to [decision or action]?
- Values are defined as strongly held beliefs, ideals, principles, or standards that inform ethical decisions or actions

### Consider the types of information needed

- Medical facts
- Patient's preferences and interests
- Other parties' preferences and interests
- Ethics knowledge
  - ◆ Codes of ethics, ethics guidelines, and consensus statements
  - ◆ Published literature
  - ◆ Precedent cases
  - ◆ Institutional policy and documents, and law
  - ◆ Outside ethics experts

### Identify the appropriate sources of information

- Face-to-face patient visit
- Direct examination of the health record and other documents
- Interviews with key staff members
- Interviews with family members and friends

### Gather information systematically from each source

- Adapt the content and depth of information to fit the needs of the case
- Collect firsthand information whenever possible
- Independently verify critical information
- Distinguish medical facts from value judgments
- Notify the attending physician before interviewing the patient

### Summarize the case and the ethics question

- Communicate the summary to key participants
- Respectfully report information from various sources
- Attempt to reconcile contradictory information
- Reformulate the ethics question, if necessary

### Determine whether a formal meeting is needed

- Prepare by communicating with key participants and reviewing relevant ethics knowledge
- Explain goals and set ground rules
- "Level the playing field"

### Engage in ethical analysis

- Apply ethics knowledge to the case and ethics question
- Apply various approaches to ethical analysis

### Identify the ethically appropriate decision maker

- Determine whether the patient has decision-making capacity
- If the patient lacks capacity, determine his/her known preferences and authorized surrogate
- Clarify the limits of the surrogate's authority
- If no surrogate is available, facilitate the process described in VA policy
- Health care professionals determine what clinical interventions are consistent with sound medical practice.
- The patient/surrogate determines whether to accept these interventions.
- The health care organization may legitimately place limits on patient/surrogate or provider choice.

### Facilitate moral deliberation about ethically justifiable options

- Offer options that may not have been considered
- Review the range of ethically justifiable options
- Cite sources to support the claim that a particular option is not ethically justifiable
- Support the ethically appropriate decision maker in the decision-making process



## Explain the Synthesis

### Communicate the synthesis to key participant

- Communicate directly to key participants
- Describe what transpired as well as the resolution and any recommendations or plans
- Indicate willingness to continue working with participants

### Provide additional resources

- Consider what might be most useful to participants
- Make available copies of articles or other publications
- Recommend websites for additional information

### Document the consultation in the health record

- Name and role of requester
- Date and time of request
- Name(s) of consultant(s)
- Description of case and ethics concern
- Ethics question
- Sources and summary of relevant information (i.e., medical facts, patient interests, other interests, ethics knowledge)
- Description of formal meetings held
- Summary of ethical analysis
- Determination of ethically appropriate decision maker
- Options considered and whether consensus was reached
- Recommendations and plans

### Document the consultation in consultation service records

- All health record notes
- Inter-consultant communications and notes
- Activities supporting the consultation process



## Support the Consultation Process

### Follow up with participant

- What happened with the case?
- Have any new ethics concerns emerged?
- Were the recommendations followed? If not, why not?

### Evaluate the consultation

- Conduct a critical self-review of each case
- Compare actual processes followed to established standards
- Determine participants' satisfaction with the consult process
- Obtain feedback from peers and supervisors
- Explore opportunities for external peer review

### Adjust the consultation process

- Consider results of follow-up and evaluation steps above
- Make changes in policies and/or procedures as appropriate

### Identify underlying systems issues

- For each case, consider whether underlying systems issues need to be addressed
- Periodically review records to look for patterns of recurrent cases or concerns
- Bring significant systems issues to the attention of the individual or body responsible for handling such concerns



## Ethics Consultation Responding to Ethics Concerns in Health Care

This card describes a practical, systematic approach for performing ethics case consultation (i.e., ethics consultation that pertains to an active patient case).

This process involves five steps:

- Clarify the Consultation Request
- Assemble the Relevant Information
- Synthesize the Information
- Explain the Synthesis
- Support the Consultation Process

These steps were designed to guide ethics consultants through the complex processes needed to effectively resolve ethics concerns relating to active patient cases. We intend this set of steps to be used similarly to the way clinicians use a standard format for taking a patient's history, performing a physical exam, or writing up a clinical case. Even when some steps do not require specific, observable action, each of the steps should be considered systematically as part of every ethics case consultation.

Although the steps are presented in a linear fashion, it should be recognized that ethics case consultation is a fluid process and the distinction between steps may blur in the context of a specific case. At times, steps may need to be repeated or performed in a different order than presented here.



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## ***Appendix 4***

### Sample Ethics Case Consultation Summary and Template

## **Sample Ethics Case Consultation Summary**

### **About the Ethics Case Consultation Summary Template**

This tool is designed to help individuals who perform health care ethics consultation summarize their cases and document their work. The template is provided here in a printed version that can also be used, in conjunction with the ethics pocket card and the CASES approach, as a worksheet while performing an ethics consultation. An electronic version of this template, which may be downloaded for local use, is available at [vaww.va.gov/IntegratedEthics](http://vaww.va.gov/IntegratedEthics).

This template is designed to help consultants generate a comprehensive summary at the end of the “Synthesis” step of each case consultation. This is useful not only for recordkeeping and documentation purposes, but also as a guide for communicating information to key participants, including family members when appropriate. Consultation summaries can also serve as a valuable educational resource to others involved in the patient’s care when placed in the patient’s health record.

The template is longer than most clinical consultation notes. However, the comprehensiveness of the form helps to ensure that the record is complete, and that steps are not overlooked in the consultation process. If a particular data field is not relevant to the case at hand, the consultant should enter “Not Applicable” to indicate to the reader that this element was considered. Since some readers will only read the final two sections (Recommendations and Plans), consultants should pay special attention to these sections and how they are phrased.

### **About the Sample Ethics Case Consultation Summary**

This sample demonstrates how the summary might look at the completion of an ethics case consultation. Please note that the names and events in the sample case are fictionalized and any similarity to actual people or events is unintentional.

## Sample Ethics Case Consultation Summary

### Requester Information

First name: Zelda      Last name: Button      Degree(s): MD Title: Chief, ICU

Role in the case:

- ☒ Physician – Staff
- ☐ Physician – Trainee
- ☐ Nurse – NP
- ☐ Nurse – RN
- ☐ Nurse – LPN
- ☐ Physician assistant
- ☐ Social worker
- ☐ Other clinical staff
- ☐ Patient
- ☐ Family member
- ☐ Other

Date of request: 2-2-05

Time of request: 9:00 AM

Timeframe (Check one): ☒ Routine ☐ Urgent

### Requester's Description of Ethics Case and Concern:

Dr. Button requested an ethics consultation to help the treatment team decide whether they should comply with the family's request for complementary or alternative therapy consistent with the teachings of Edgar Cayce. She described the therapies as "fumes of apple brandy into the patient's endotracheal tube, a nutritional mixture of ground figs, cornmeal and milk via the patient's NG tube, and olive oil rubs to the patient's back and chest."

Steps taken to resolve the concern prior to ethics consultation:

Team members discussed the case.

Type of assistance requested (Check all that apply):

- ☒ Forum for discussion
- ☒ Conflict resolution
- ☒ Explanation of options
- ☐ Values clarification
- ☐ Policy interpretation
- ☐ Recommendation for care
- ☐ Moral support

### Patient Information

First name: Benjamin Last name: Ruiz

Age: 72 Gender: ☒ Male ☐ Female

Clinical service (check one):

☒ Medical and Subspecialty Care (including Neurology)

☐ Geriatrics and Extended Care/Rehabilitation Medicine

☐ Mental Health

☐ Surgical and Anesthesia

☐ Other (Specify):

Patient's location: ICU, Bed 1

Attending physician: Zelda Button, MD

Was the attending notified? ☒ Yes ☐ No If no, explain:

### Ethics Question (Use one of the following formats):

Given [uncertainty or conflict about values], what decisions or actions are ethically justifiable?

- or -

Given [uncertainty or conflict about values], is it ethically justifiable to [decision or action]?

#### *The ethics question is:*

Given that the team recognizes the importance of shared decision making and wants to honor the surrogate's treatment request but feels that doing so might compromise their professional standards, is it ethically justifiable to refuse the request for such therapy?

### Ethics Consultants

Primary: Salvatore Garibaldi, RN

Other (List): Jane Ostrow, MD

### Decision-Making Capacity

Does the patient have decision-making capacity?

☐ Clearly yes

☒ Clearly no

☐ Partial/fluctuating/unclear (If checked, explain):

### Surrogate Decision Maker

Does the patient have an authorized surrogate? ☒ Yes ☐ No (If no, explain):

Name of surrogate: Robert Ruiz

Surrogate's contact information: (111) 555-1212

Surrogate's relationship to patient:

- ☐ Health Care Agent
- ☐ Legal guardian or special guardian
- ☐ Next-of-kin (If checked, specify):
  - 1) ☐ Spouse
  - 2) ☒ Child
  - 3) ☐ Parent
  - 4) ☐ Sibling
  - 5) ☐ Grandparent
  - 6) ☐ Grandchild
  - 7) ☐ Close friend

#### *Comments about surrogate selection:*

The team does not expect the patient to regain decisional capacity anytime soon. The patient's spouse has relinquished decision-making responsibility to the son.

### Advance Directive

Does the patient have an advance directive? ☐ Yes ☒ No

If yes, did the consultant(s) review the directive? ☐ Yes ☐ No (If no, explain):

If yes, summarize the relevant content of the directive, using direct quotes if possible:

### Data Sources and Summary

The consultant(s) collected data from the following sources:

Examination of the patient's medical record: ☒ Yes ☐ No (If no, explain):

Face-to-face patient visit: [ x ] Yes [ ] No (If no, explain):

Other people interviewed and their roles (staff, family/friends, etc.):

Dr. Button, Dr. Mary Cola (resident), Betty Brown, RN (nurse), Mrs. Ruiz (wife), Robert Ruiz (son).

The *medical facts* of the case are summarized as follows:

The patient is a 72-year-old male who has been receiving treatment for pulmonary TB in the ICU for several weeks. He is intubated and receives nutrition via an NG tube. He is unable to be weaned from the ventilator at this time. He is clinically stable and tolerating the current medical regimen (4 anti-TB meds, nutritional and other supportive care), although he remains weak and nutritionally compromised. Dr. Button is cautiously optimistic that the patient will recover from the TB and be able to be extubated.

The *patient's preferences and interests* in the case are summarized as follows:

The patient is unable to participate in medical decision making due to confusion. His wife, who speaks only Spanish, has indicated through an interpreter that she wishes all medical decisions to be made by their only child, Robert. The patient has not completed an advance directive and was not a follower of Edgar Cayce.

*Other parties' preferences and interests* in the case are summarized as follows:

The patient's son has requested that his father receive alternative therapies for TB as described in the teaching of Edgar Cayce. Specifically, he requested that the patient be allowed to inhale fumes of apple brandy steeped in a charred wooden keg via his endotracheal tube in addition to current TB medications. He also wants the patient's diet to be changed to a mixture of ground figs, cornmeal and milk given through the patient's NG tube. Finally, he would like to be able to rub the patient's back and chest with olive oil several times a day. The son said his request was based on what he thought was best for his dad rather than any previous preferences that his father had expressed. The son stated that he could not bear the thought of losing his father and was just trying to make sure that everything that could be done for him was being tried. He believes the alternative therapies will help make his father well.

The attending physician's reluctance to comply with the son's wishes is based primarily on concerns for safety. She explained that the fumes were untested in the respiratory circuit and might damage the machinery or cause an unforeseen reaction. She also postulates that the proposed diet will clog the feeding tube and she does not feel that it would provide the patient with complete nutrition. Clogged tubes would result in more tube changes and discomfort for the patient. Since the son would provide the proposed therapies, there are added concerns that staff could not meaningfully control the composition of the fumes and feeding mixture. Liability and accreditation issues may exist. The team is reluctant to even allow the olive oil body rubs because this practice deviates from usual nursing protocols and might attract insects to the room.



### Summary of Ethics Knowledge

The following sources of ethics knowledge were reviewed or consulted:

- ☒ VA policy
- ☐ Professional codes and guidelines
- ☒ Published literature
- ☐ Precedent cases
- ☐ Outside ethics experts
- ☐ Other (Specify):

The *ethics knowledge* relevant to this case is summarized as follows:

Edgar Cayce was a psychic who responded to diverse questions, including health-related issues, after putting himself into trance states. Although he died in 1945, he still has many followers today. The therapies that the patient's son proposed are in fact based on Edgar Cayce's teachings but have not been corroborated in the medical literature.

Although surrogates can choose from options offered by the treatment team, including the option of refusing treatment, they have no authority to compel the treatment team to apply therapies that are outside the standard of medical practice, or that may cause the patient harm. Furthermore, surrogates are obligated to make decisions based on the patient's values and previously stated preferences and, only if they are not known may the surrogate apply other reasoning to the decision (i.e., best interests). [VHA Handbook 1004.1 and local informed consent policy describe procedures, roles and responsibilities for surrogate decision-making.]

### Summary of Formal Meetings

Did formal meeting(s) take place? ☒ Yes ☐ No

If yes, list date(s), time(s), and attendees, and summarize:

On 2/4/2004 at 2 PM, the ethics consultation team met with members of the health care team (attending, resident, nurse) and the patient's family (wife, son). The team reviewed the patient's medical condition and explained to his son that they were not inclined to comply with his requests because they felt that the current treatment regimen gave his father the best chance for recovery and was within accepted medical practice standards. The team also outlined the potential harm's of the alternative therapies. The ethics consultants reviewed the roles and responsibilities of surrogate decision makers.

The son understood his role as surrogate decision maker as well as the team's safety concerns but felt that the team was "closed minded" about the teachings of Edgar Cayce and that his wishes were being dismissed without thought. Although he considered the information carefully, he still felt that the alternative therapies he proposed were best for his father. At no time did the son object to the current treatment regimen. He only wished to add the alternative therapies to the existing treatment plan.

### Ethics Analysis

Describe how the relevant ethics knowledge applies to the case and the ethics question:

It is important to note that the ethically appropriate decision maker in a particular case is

based on the circumstances as well as the nature of the decision to be made. Specifically, it is important to distinguish between the patient's right to choose among medically acceptable options, and the provider's duty to offer the patient choices that are consistent with their professional judgment. Decision making rests with patients, or authorized surrogates, in cases where patients or surrogates are choosing among medically appropriate options for care. However, when the decision is about determining what particular treatments or procedures are consistent with sound medical practice, clinicians are the appropriate decision makers. When clinicians make medical decisions, they must assure that they do so on the basis of sound professional judgment, and must be careful not to abuse their authority by substituting their own preferences and values for those of the patient.

### Options Considered

Describe the options considered and explain whether each option was deemed ethically justifiable and why:

1. Supply all the alternative therapies requested by the surrogate. (This option was not deemed ethically justifiable, because the health care team indicated that some of the therapies would likely cause harm.)
2. Deny the surrogate's request for any alternative therapies. (This option was deemed ethically justifiable, but only if the health care team first explored whether some aspects of the request could be reasonably accommodated without imposing undue burdens.)
3. Negotiate a treatment plan that includes only the alternative therapies that are believed to be safe and consistent with professional standards. (This option was deemed ethically justifiable as it inherently respects both professional and surrogate roles as well as optimizing the patient's safety.)

### Ethically Appropriate Decision Maker

Who is the rightful decision maker(s) regarding the critical decision(s) in the case?:

Dr. Zelda Button, attending physician.

*Explain:* The critical decision in the case—whether particular therapies should be offered—is a matter of professional judgment. Therefore, the ethically appropriate decision maker is Dr. Button, the responsible clinician.

### Agreement

Did the relevant parties reach agreement in the case? [ ] Yes [x] No (If no, explain):

The son understands that the decision is outside of his authority but he continues to feel that his preferences should be honored. Dr. Button continues to resist any alternative therapies, but agreed to try to keep an open mind.

### RECOMMENDATIONS

1. The team should consider the ethical analysis and the options as detailed above.
2. The team should review some of the literature the ethics consultants provided on complementary/alternative medicine. Patients are increasingly requesting/expecting clinicians to integrate alternative care into the treatment plan. The recommended

articles discuss ways of approaching complementary and alternative medicine in a manner that minimizes potential harm and maximizes the aspects that play a role in a healing relationship.

3. An “all or nothing” approach to care planning should be avoided when at all possible. The team should negotiate a treatment plan that includes only the requested therapies that are known to be safe and are reasonable for staff to allow. For example, the treatment team may wish to give further consideration to the request that the son be allowed to rub olive oil on his father’s chest several times a day, at least on a trial basis. If the son is permitted to rub olive oil on the father’s chest, staff should assess to ensure the patient is not uncomfortable or showing evidence of resisting, and that there are no adverse effects from this activity.
4. The wife and son should be offered support services such as social work or chaplaincy.

## **PLANS**

The team will further explore the possibility of allowing the use of one or more alternative therapies, especially the olive oil. The ethics consultant team will check in with the treatment team and the patient’s family in one week.

### **Ethics Case Consultation Summary Template**

#### **Requester Information**

First name:      Last name:      Degree(s):      Title:

Role in the case:

- ☐ Physician – Staff
- ☐ Physician – Trainee
- ☐ Nurse – NP
- ☐ Nurse – RN
- ☐ Nurse – LPN
- ☐ Physician assistant
- ☐ Social worker
- ☐ Other clinical staff
- ☐ Patient
- ☐ Family member
- ☐ Other

Date of request:      Time of request:

Timeframe (Check one): ☐ Routine ☐ Urgent

#### **Requester's Description of Ethics Case and Concern:**

Type of assistance requested (Check all that apply):

- ☐ Forum for discussion
- ☐ Conflict resolution
- ☐ Explanation of options
- ☐ Values clarification
- ☐ Policy interpretation
- ☐ Recommendation for care
- ☐ Moral support

**Patient Information**

First name:

Last name:

Age:

Gender: ☐ Male ☐ Female

Clinical service (check one):

- ☐ Medical and Subspecialty Care (including Neurology)
- ☐ Geriatrics and Extended Care/Rehabilitation Medicine
- ☐ Mental Health
- ☐ Surgical and Anesthesia
- ☐ Other (Specify):

Patient's location:

Attending physician:

Was the attending notified? ☐ Yes ☐ No

If no, explain:

*Ethics Question* (Use one of the following formats):

Given [uncertainty or conflict about values], what decisions or actions are ethically justifiable?

- or -

Given [uncertainty or conflict about values], is it ethically justifiable to [decision or action]?

*The ethics question is:*

**Ethics Consultants**

Primary:

Other (List):

**Decision-Making Capacity**

Does the patient have decision-making capacity?

- ☐ Clearly yes
- ☐ Clearly no
- ☐ Partial/fluctuating/unclear (If checked, explain):

### Surrogate Decision Maker

Does the patient have an authorized surrogate? ☐ Yes ☐ No

If no, explain:

Name of surrogate:

Surrogate's contact information:

Surrogate's relationship to patient:

- ☐ Health Care Agent
- ☐ Legal guardian or special guardian
- ☐ Next-of-kin (If checked, specify):
  - 1) ☐ Spouse
  - 2) ☐ Child
  - 3) ☐ Parent
  - 4) ☐ Sibling
  - 5) ☐ Grandparent
  - 6) ☐ Grandchild
  - 7) ☐ Close friend

Comments about surrogate selection:

### Advance Directive

Does the patient have an advance directive? ☐ Yes ☐ No

If yes, did the consultant(s) review the directive? ☐ Yes ☐ No

If no, explain:



If yes, summarize the relevant content of the directive, using direct quotes if possible:

**Data Sources and Summary**

The consultant(s) collected data from the following sources:

Examination of the patient's medical record: ☐ Yes ☐ No

(If no, explain):

Face-to-face patient visit: ☐ Yes ☐ No

If no, explain:

Other people interviewed and their roles (staff, family/friends, etc.):

The *medical facts* of the case are summarized as follows:

The *patient's preferences and interests* in the case are summarized as follows:

*Other parties' preferences and interests* in the case are summarized as follows:

## Summary of Ethics Knowledge

The following sources of ethics knowledge were reviewed or consulted:

- ☐ VA policy
- ☐ Professional codes and guidelines
- ☐ Published literature
- ☐ Precedent cases
- ☐ Outside ethics experts
- ☐ Other (Specify):

The *ethics knowledge* relevant to this case is summarized as follows:

### Summary of Formal Meetings

Did formal meeting(s) take place? ☐ Yes ☐ No

If yes, list date(s), time(s), and attendees, and summarize:

## Ethical Analysis

**Options Considered**

Describe the options considered and explain whether each option was deemed ethically justifiable and why:

**Ethically Appropriate Decision Maker**

Who is (are) the rightful decision maker(s) regarding the critical decision(s) in the case?:

*Explain:*

**Agreement**

Did the relevant parties reach agreement in the case?: [    ] Yes [    ] No  
(If no, explain):

**RECOMMENDATIONS**

**PLANS**

---

## ***Appendix 5***

### Resources

## Resources

### Books & Monographs:

Ahronheim JC, Moreno JD, Zuckerman C. *Ethics in Clinical Practice*, 1<sup>st</sup> ed. Boston: Little Brown;1994.

American Society for Bioethics and Humanities, Task Force on Standards for Bioethics and Humanities. *Core Competencies for Health Care Ethics Consultation: The Report of the American Society for Bioethics and Humanities*. Glenview, IL: American Society for Bioethics and Humanities;1998.

Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*, 5<sup>th</sup> ed. New York: Oxford University Press;2001.

Devettere RJ. *Practical Decision Making in Health Care Ethics: Cases and Concepts*, 2<sup>nd</sup> ed. Washington, DC: Georgetown University Press;2002.

Dubler NN, Liebman CB. *Bioethics Mediation: A Guide to Shaping Shared Solutions*. New York: United Hospital Fund of New York;2004.

Fletcher JC, Boyle R. *Introduction to Clinical Ethics*, 2<sup>nd</sup> ed. Frederick, MD: University Publishing Group;1997.

Jonsen A, Siegler M, Winslade W. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*, 5<sup>th</sup> ed. New York: McGraw Hill;2002.

Jonsen A, Toulmin S. *The Abuse of Casuistry: A History of Moral Reasoning*. Reprinted. Berkeley: University of California Press;1990.

La Puma J, Schiedermayer D. *Ethics Consultation: A Practical Guide*. Boston: Jones and Bartlett Publishers;1994.

Lo B. *Resolving Ethical Dilemmas*, 2<sup>nd</sup> ed. Philadelphia: Lippincott Williams & Wilkins;2000.

Mappes TA, DeGrazia D. *Biomedical Ethics*, 5<sup>th</sup> ed. New York: McGraw-Hill;2001.

Post SG, editor. *Encyclopedia of Bioethics*, 3<sup>rd</sup> ed. New York: Macmillan Reference USA;2004.

Steinbock B, Arras J, London, AJ. *Ethical Issues in Modern Medicine*, 6<sup>th</sup> ed. Boston: McGraw-Hill;2003.

Monagle JF, Thomasma, DC. *Health Care Ethics: Critical Issues for the 21st Century*, 2<sup>nd</sup> ed. Sudbury, MA: Jones and Bartlett;2004.

**Online Resources:**

American Society for Bioethics and Humanities (ASBH)  
[www.asbh.org](http://www.asbh.org)

Bioethics.net – The American Journal of Bioethics  
[www.bioethics.net/](http://www.bioethics.net/)

Center for Bioethics, University of Pennsylvania  
[www.bioethics.upenn.edu/](http://www.bioethics.upenn.edu/)

Center for the Study of Bioethics, Medical College of Wisconsin  
[www.mcw.edu/bioethics/index.html](http://www.mcw.edu/bioethics/index.html)

Kennedy Institute of Ethics, Georgetown University  
[kennedyinstitute.georgetown.edu/site/index.htm](http://kennedyinstitute.georgetown.edu/site/index.htm)

National Bioethics Advisory Commission (NBAC)  
[www.georgetown.edu/research/nrcbl/nbac/](http://www.georgetown.edu/research/nrcbl/nbac/)

National Center for Ethics in Health Care  
[www.va.gov/vhaethics](http://www.va.gov/vhaethics)

National Reference Center for Bioethics Literature, Georgetown University  
[www.georgetown.edu/research/nrcbl/nrcl/index.htm](http://www.georgetown.edu/research/nrcbl/nrcl/index.htm)

Nuffield Council on Bioethics  
[www.nuffieldbioethics.org/](http://www.nuffieldbioethics.org/)